

Beyond 'I'm a Diabetic,' Little Common Ground

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Lisa Reed, whose son has Type 1 diabetes, remembers the first time she wept in a United States senator's office. She was with other parents, appealing for money to find a cure for the disease, which most often surfaces in children.

Mortified, she turned to apologize. There were still four Congressional offices to visit.

"Lisa," another parent asked, "can you do that four more times?"

Wielding such emotional power, the parents of Type 1 diabetics have been as relentless as lionesses in their pursuit of money for medical research to help their children.

As volunteers for the Juvenile Diabetes Research Foundation, they collect far more money per patient for Type 1 diabetics than older and larger organizations that fight diseases with many, many more cases.

Among the illnesses that have been outpaced is a major disease, now epidemic in proportions, with a similar name: Type 2 diabetes.

Type 2, which most often affects the old and overweight, now afflicts some 20 million Americans and is the nation's fastest growing health problem. But it draws little more research money than Type 1, a malfunction of the immune system that affects one million people in the United States.

Even public health authorities who try to avoid viewing one disease in the context of another acknowledge that it is hard not to notice the outsize fundraising success of Type 1 in contrast with Type 2.

It is among the many points of distinction between two groups who share the label diabetic and the risks that arise from having elevated sugar in their blood — though not much else.

Most Type 1 diabetics develop the

disease as children, without warning, on the basis of genetic factors. They are quite often thin. They come from all walks of life, neighborhoods and ethnicities.

Their chief advocates are parents of children with Type 1, a group that includes skilled, upper-income professionals devoted to finding a long-sought cure, which many think is approaching.

People with Type 2, on the other hand, are far more likely to be old and poor, overweight and not white, although this disease also stems, in part, from genetic factors. The risk increases with age. Because their disease is associated with eating and inactivity, they routinely encounter less sympathy. Often they are stigmatized as undisciplined.

As a group, Type 2 diabetics tend to be less organized and less forceful in advocating for themselves. They cannot argue as convincingly that more money might produce a medical cure anytime soon.

Yet the number of Type 2 diabetics is so large, and growing so rapidly, that Type 1 parents often say they fear that their children's plight is being lost in the din of the larger problem with the similar name.

They often bristle when their children are mistaken for Type 2 diabetics, fearful that their children, and their own fundraising efforts, are being muddied by the stigma that clings to the other disease.

More than three decades ago, these concerns helped convince the parents of people with Type 1 to create their own organization, the Juvenile Diabetes Research Foundation, dedicated solely to curing that disease. Many people with Type 1 now raise money for the foundation, not for the American Diabetes Association, with which they were once affiliated.

The A.D.A., an older organization that still represents the interests of all diabetics, is now viewed by many as primarily geared toward Type 2 diabetes.

Some scientists and public health officials question whether the efforts to find a cure for Type 1 siphon money from research into the sweep of issues relating to Type 2.

"I understand where the separatist attitude of the Type 1 people is coming from," said Rudolph L. Leibel, director of research at the Naomi Berrie Diabetes Center at Columbia University. "But I question whether it's in anyone's best interests."

Outraising, Outspending

The Juvenile Diabetes Research Foundation raises and spends more money than other groups that support research on chronic diseases with similar caseloads.

DISEASE	ESTIMATED U.S. CASES (MILLIONS)	MAIN PRIVATE RESEARCH GROUP	2004 RESEARCH SPENDING (MILLIONS)
Type 1 diabetes	1	Juvenile Diabetes Research Foundation	\$98
Multiple sclerosis	0.4-1	National Multiple Sclerosis Society	35
Parkinson's disease	0.5-1.5	Michael J. Fox Foundation for Parkinson's Research	12
Lupus	0.7-2	Alliance for Lupus Research	2

Sources: Annual reports and financial statements

The New York Times

The Type 1 forces make no apologies. They argue that a Type 1 cure is possible, and that a dollar devoted to Type 1 is not necessarily one taken from Type 2.

“I hope that people are doing this work for every disease,” Ms. Reed said. “But this is the one that’s in our family, and we want to beat it.”

A Parent’s Perspective

To understand why Type 1 parents feel so strongly, it helps to understand that in the world of diabetes, their children are the minority. Type 2 dominates the public view of diabetes. Often, part of that image is that Type 2 diabetics are at fault for their disease.

Actually, some scientists question how much individual choice has contributed to the rise in obesity, since so much is propelled by broad social changes. And some Type 2 diabetics are far from fat.

Nonetheless, Type 2 diabetics routinely confront the view that they inflict the problem on themselves. And Type 1 diabetics say they are routinely swept up in that stigma.

“People think diabetes is about being fat,” said Carolyn Goldfarb, the mother of a 4-year-old, Brooke, who has Type 1. “My daughter isn’t fat; she’s beautiful.”

California officials recently got a striking insight into the minds of parents whose children have Type 1.

To address the epidemic of obesity, the state ran a series of hard-hitting television advertisements that ridiculed junk food and showed sweet-faced preschoolers asking questions like “Can I have some fat?” or “Dad, can you buy me some diabetes?”

The advertisements were aimed at parents of children in danger of developing Type 2. But there was little response from that audience.

Instead, parents of children with Type 1 barraged the state with e-mail messages and phone calls, furious that the ads had referred to diabetes without mentioning Type 2.

The ads lumped all diabetics together, the parents said, implying that Type 1 diabetics were somehow to blame for their disease.

“We never anticipated this intensity of feeling about making the distinction,” said Kris Perry, executive director of the state agency that produced the ads. “The

responses were very emotional, coming from a place of people feeling really hurt.”

The response would not have surprised anybody who has spent time with parents of Type 1 children. In play dates, support groups and conversation, they often express frustration that their children are mistakenly thought to have Type 2.

“I wish it had a different name,” said Ms. Goldfarb, of Short Hills, N.J.

Without much prompting, parents will rattle off the athletes and svelte stars who have Type 1 — Gary Hall, the Olympic gold medal-winning swimmer; Adam Morrison, the Gonzaga University basketball star, Halle Berry — as if to prove that sloth plays no part in it.

“I really find it hard to take seriously the complaints of Type 2 diabetics, who, in my view, brought this on themselves,” said Harry Mahaffey, a 15-year-old champion fencer from Los Angeles who has Type 1. “With Type 1 diabetes, there is absolutely nothing tied to my lifestyle, and this is something over which I had absolutely no control. But people sometimes suggest that it’s because I ate too much sugar or something, and that drives me crazy.”

Personal, and Polished

Senator Susan Collins of Maine remembers exactly when she became interested in diabetes: a 1997 meeting with Type 1 families that had been arranged by the juvenile diabetes foundation. The children showed her how they injected insulin and pricked their fingers to test their blood every few hours.

“It broke my heart,” she said. “I remember this little boy telling me how many thousands of shots he had given himself.”

Senator Collins, now Republican co-chairwoman of the Senate Diabetes Caucus, still marvels at the shrewdness of the foundation, which is known in Washington for its well-trained corps of parent volunteers and their persistent, poignant appeals.

The foundation typically outperforms, in lobbying and fund-raising, nearly every other interest group built around a particular disease.

In part because of its efforts, the



Moira McCarthy, left, lobbies for Type 1 diabetics like her daughter, Lauren Stanford, 14.

government spends more money fighting Type 1 than it does to combat many other serious, chronic diseases. The government does not provide specific breakdowns of spending by disease. But experts said more than 30 percent of the \$1 billion diabetes research budget of the National Institutes of Health was directed toward Type 1, which accounts for about 5 percent of diabetics. More, maybe as much as half, goes toward Type 2 research and the rest is split on research that benefits understanding of both diseases. When it comes to raising money on its own, the juvenile diabetes foundation generates much more, per person afflicted, than other health care organizations. Last year, the foundation raised \$183 million, compared with \$209 million raised by the much larger American Diabetes Association.

More than half of the foundation’s budget, \$100 million, was devoted to research to find a cure. Only the American Cancer Society and the American Heart Association, whose work affects vastly more people, spend more on research.

Researchers are following several paths toward a potential Type 1 cure, like finding a way to make the insulin-producing cells in the pancreas more resistant to assault by the immune system. Many scientists are looking for the trigger that starts that attack — viruses and food allergies are among the suspects — and for ways to bypass it, while others are looking for ways to stimulate the growth of new insulin-producing cells. The ultimate answer would be to turn off the immune response that destroys



Lisa and Jack Reed, whose son has Type 1 diabetes, heading to Senator Trent Lott's office on Capitol Hill. Poignant appeals by parents have powered the Juvenile Diabetes Research Foundation's fund-raising successes.

those cells, a breakthrough that could have implications for many other "autoimmune" diseases, like multiple sclerosis or lupus.

The American Diabetes Association, which also uses its budget to finance treatment and public awareness campaigns, spent half as much as the foundation on research, which is divided between Type 1 and Type 2.

Whereas the A.D.A. is a doctor-based organization, founded by medical professionals, the foundation is very much powered by parents.

"My daughter has been hospitalized 14 times because of diabetes, and I can't think of a better motivation than that," said McCarthy, a volunteer from Plymouth, Mass. "I call Ted Kennedy's office and, I promise you, they know who I am."

Similarly, Ms. Reed and her husband, Jack, are ideal emissaries to lobby Mississippi's conservative Congressional delegation. Attractive, eloquent and religious, the Reeds own a small clothing business and have made their pitch so many times over the years that they are well known in legislative offices.

In March, the Reeds, who live in Tupelo, joined hundreds of volunteers who fanned out over Capitol Hill, armed with the blue cards listing the foundation's talking points. "You're so

much stronger for your children than you could ever be for yourself," said Ms. Reed, who still occasionally sheds a tear at such meetings.

Type 1 families meet every year with nearly all members of Congress or their aides. Volunteers are trained on issues of substance and protocol, such as how to be both polite and insistent. Whenever possible, the visitors include children, some young enough to climb into Congressional laps.

Representative Mike Castle, a Republican from Delaware, says he offers pointers to many interest groups seeking attention from Congress: Have ordinary people — preferably the members' own constituents — make the appeal, not professional lobbyists. Arrange meetings often, not only in Washington, but also in the lawmakers' home territory, when Congress is not in session and they are not as busy.

Everyone understands the advice, he said, "but the J.D.R.F. does it."

Related but Not the Same

The confusion between Type 1 and Type 2 diabetes exists despite the fact that, as a matter of science, the diseases are quite distinct.

Both types carry the same long-term risks from elevated blood sugar: kidney failure, heart disease, blindness.

But Type 1 also carries constant and considerable short-term risk. Sudden, extreme blood sugar lows and highs can lead to hospitalization, even death. As a result, parents will often not leave Type 1 children with people who are not well versed in the disease.

In Type 1, the body stops making insulin, a hormone needed to process sugar, or it makes too little. Patients must take insulin shots, usually several a day, or they die.

In most cases of Type 2, the body produces plenty of insulin but resists using it — a condition usually treated with pills and lifestyle changes. In severe cases, people with Type 2 must inject insulin, but the ill effects of their disease often do not surface for years.

In some respects, experts say, the immediacy of risk in Type 1 is a built-in prod, one that helps those afflicted practice the sort of discipline in diet and vigilance in blood sugar monitoring that

is often overlooked by Type 2 diabetics. If people with Type 1 stop measuring their blood sugar, they can lapse into unconsciousness. For a Type 2 diabetic, the consequence may not be apparent for years.

For some Type 1 families, the all-consuming diligence required by Type 1 is another point of distinction from Type 2.

"If somebody told me all my kid had to do was eat healthy, lose weight and exercise, and she wouldn't have to deal with this any more, for me, that would be the best news in the world," said Karen Nicholas, whose daughter, Addie, 5, has Type 1. "I don't want to seem resentful, but for us, there's no choice."

Type 2 diabetics, on the other hand, tend to give little thought to Type 1 diabetics. Many are so busy with work, children and their health problems that it barely occurs to them to view their own disease, or what other people think of it, as a social cause.

And they often live in communities where so many of their neighbors have the same disease that they cannot envision themselves as a special interest group.

In a Type 2 diabetes education class at Montefiore Medical Center in the Bronx this spring, attended primarily by people in their 60's and 70's, just one student knew much about Type 1, and only because a relative had it.

No one had ever been involved in a diabetes organization or joined a fund-raising march. No one had any sense that confusion over Type 2 diabetes was often a source of concern for Type 1 diabetics.

"I've never heard any of that," said Mary Jones, 48. "Why would they have a problem with us?"

Type 2 diabetics do not necessarily have it easier, even if they generally enjoy childhoods unburdened by illness, said Howard Steinberg, producer of a CNBC program, dLifeTV, that focuses on both types.

"Type 1's, they've grown up with that discipline so ingrained in them," he said. "But when somebody tells you when you're 50, you've got to change everything about the way you eat, lose weight, start exercising, check your blood sugar, that's a heck of a lot harder than when you're 5."



At a Type 2 diabetes class in the Bronx, Mary Jones wasn't aware that confusion between types troubled those with Type 1.

He would get no argument from the students at Montefiore. Even after the course, only two had what is considered good blood sugar control. Several admitted they do not check their sugar or take their medication daily, and that they still eat poorly.

"A child can learn and change so much more easily," said Ms. Jones. "But we already learned and we learned wrong."

Colleague or Competitor?

If more money were devoted to Type 2 research, scientists say, diabetics like Mrs. Jones might benefit from studies

into issues like how to overcome insulin resistance or why insulin-producing cells die in severe cases.

Some doctors argue that the large amount of money committed to Type 1 might be undercutting money for Type 2, because they compete for the same finite pool of money. Others say they do not believe that this is true, though it might have been in years past, and they argue that what is learned about one disease helps with both.

The American Diabetes Association does not assert that efforts on behalf of Type 2 diabetics have been hurt by the success of the juvenile diabetes foundation.

"Any research that potentially improves the care of diabetes is valuable," said Dr. Robert A. Rizza, president of the association. "The resources for diabetes research in general have not been adequate. But because more than 90 percent of the cases are Type 2, the inadequacy is much greater there."

Of all the money spent annually on diabetes research, not only public but also private, experts estimate that about a third goes toward Type 1, about 40 percent is spent on Type 2, and the rest applies to both diseases.

Asked why Type 2 has had a hard time finding funding, given its prevalence, Dr. Rizza said, "Our society considers

obesity and sedentary lifestyle a matter of blame, and that does affect the politics and the money."

Some scientists say the juvenile diabetes foundation's single-minded focus on finding a Type 1 cure means research useful to understand both types is neglected. Recent research shows signs of overlap between the types. A surprising number of people with Type 2, for example, show immune system oddities typical of Type 1.

There is even talk of a Type 1½.

Dr. Leibel of Columbia said he was somewhat frustrated by the foundation's focus.

"They want to find a cure more than they want to understand the underlying biology," he said. "But there's a convergence of these two diseases at the cellular level and if we understood that better, we could help both."

Dr. Robert Goldstein, chief scientific officer of the foundation, defended his organization's approach. Tangible progress toward a cure trumps everything, he said.

"If you have a child with this disease and I say I want you to donate money," he said, "would you rather I invest it in basic science that may or may not pay off 20 years from now, or in something that could have high impact in the next three years?"