



In *Growing Up Again: Life, Loves and Oh Yeah, Diabetes*, Mary Tyler Moore, international chairman of the Juvenile Diabetes Research Foundation, recounts the years since her

diagnosis with type 1. With humor and a sharp eye for detail, she reveals the touching and often hilarious process of coping and conquering the challenges of the disease. In this excerpt from the just published book (St. Martin's Press, March 2009), she shares her experiences as JDRF's chairman over the past 25 years with a look to the future. We thank Ms. Moore for generously donating all of the author's proceeds from the sale of the book directly to JDRF.

Owning Diabetes

It took me years and years to get to the point where I could announce to the world, “I am Mary Tyler Moore, and I have diabetes.” But announce it I did, in 1984 when I agreed to become the chair of the then Juvenile Diabetes Foundation. I’d already made a couple of public service announcements on television asking for donations to JDF, but the spots said nothing about my also being a diabetic. I felt virtuous and yet protected from public scrutiny of my “disease.” But JDF (now JD RF) was, and is a remarkable foundation; 85 percent of the staff is made up of volunteers, and this allows the organization to give more than 80 percent of its funds to support scientific research and related education. It annually receives top rankings from independent sources that rate charities. So I was honored to be asked to affiliate myself with it and its serious work funding medical research.

It all happened when Gloria Pennington, the newly appointed executive director, sat me down (it was on the set of some show) and made her persuasive pitch. Sipping tea for two, we chatted about the latest findings in the disease, office gossip (never anything good there), and then—“Mary, would you consider becoming the chairman of JDF? We’ve done some testing on how people feel about you, and apparently they trust you. You are a diabetic and they believe what you say, and admire how you’ve conducted your life. The board of directors has met and unanimously agreed that you’re the right person.”

With terror coursing through my veins, I pressed my knees together in an attempt to stop their shaking. What would I do as this, ah, p ... person? I remember asking her.

She replied, “We’d like you to agree to go to Washington, D.C. from time to time to ask for increased funding from the government, talk to Congress about how much this disease is costing (\$132 billion in 2002. This included a doubling of the direct costs from \$44 billion to \$91.8 billion.) If you’re available, we’d ask you to attend a few fundraising dinners. We’d like you to make

more public service television spots, but now as chairman you’d relate that you too are a person with juvenile diabetes.”

I wasn’t keeping it a secret. It just wasn’t as widely known as it would be after I made a statement like that! A statement? Well, I mean, you don’t just mention something like that.

I have to admit, Gloria’s chairman request caused the MTM smile to contort a bit, but for reasons you might not guess. My mind was clicking with these questions: If I tell the public that I have diabe-

tes, won’t they say to themselves, “Well, it can’t be all that serious a disease. Look at her, she’s energetic, bursting with health, never sick! There are much worse diseases than diabetes.” The other end of the seesaw (do they still have those?) was my fear that as the public watched me acting my brains out they would be thinking, “Oh it’s sad, she has diabetes and from what I hear, there is no cure for it.”

JDF could take a bad blow from the first scenario and I wouldn’t like the second one even a bit.

I finally put a stop to my ambivalence by thinking, “Just do what you know is right, stupid.” (There she was, again, annoying, but right.)

The first time I headed to the Hill for JD RF, I remember wondering if I should wear my eyeglasses so I could read my testimony better, or would I look less ill without them? But maybe if I looked less ill, we’d lose the impact of how serious diabetes really is. So, here I am back on the merry-go-round of wanting to look hearty, but not too hearty. And as to that lack of self confidence, all I have to do is remember Spencer Tracy’s answer when asked the secret of his success: “Show up on time, hit your marks, and tell the truth.”

In my early visits and testimony, JDF was a very small organization. In our war

chest we’d collected enough money to turn over to research between eight million and 10 million dollars a year (we now give approximately 200 million dollars a year.). Sure, we had a D.C.-based law firm helping us out (mostly pro bono) and we had good relationships on the Hill dating from our founding “moms” early efforts to get Congress to recognize the need for more diabetes research.

Today, we’ve not only added another letter to our name, but we’ve become a partner with government. We can say to

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those on the Hill, “We’re not asking for a handout as we search for the cure; we’re your partners. And we’re every bit as determined as those founding moms.”

Every other year, a group of 100–200 children representing the 50 states from which they come are brought together by JD RF in Washington, D.C. to tell Congress their personal stories of living with diabetes and to ask, as I do, that more money be given to research for a cure. They spend two and a half days visiting the Hill speaking both formally in the Senate hearing room as well as individually to the representatives in their offices as Little Lobbyists.

Some of the time is spent as a group getting to know each other. At the welcoming dinner, I asked each of the children to stand and introduce himself or herself, giving their state and age. They range from three to 18 years and a finer bunch of kids you’d have trouble collecting. “I’m Stewart Slatterly from Texas and I’m nine years old.” “I’m Nancy Brown from California and I am six years old.” “I’m Mia—I wanna pee.” And so it went—really, that’s a quote! Finally, it was my turn. “I’m Mary Tyler Moore from New York and I’m 62 years old.”

Can you imagine the tension these brave young visitors must feel in Washington,

D.C.—Capitol Hill, where the laws we live by are made? The houses and offices of our country's history. The huge American flags everywhere you look! Why, it makes you feel that losing the last soccer game wasn't the worst thing ever. This is the worst thing ever: Having to talk to these very important people is the worst thing ever. I'm not smart. Maybe I'll wreck everything.

But I love talking to these kids, answering their questions, hearing their triumphs, their fears, and about Laura's new boyfriend who isn't diabetic. They give me the gift of friendship and support. By sharing their stories with me, I am able to witness the courage of our children with type 1, and I find new strength to face my own day-to-day challenges of life with diabetes.

Over the years I've had so many people, youngsters and adults, thank me for "doing what you do." But no one can know how much it does for me! The effort is my gift to myself.

When I first joined JDRE, we were small, but we were no less influential. The passion of our families, who would invite future giants of diabetes research to dinner, came through clearly—shaping these young scientists' thinking and animating their pursuit of research solutions. Many of the advances we are seeing today had their germination in the relationships that were built back then.

One of the most special parts of my work with JDRE is the partnership that my husband Robert and I formed to help the organization mature and flourish. He had dedicated countless hours and days and months and years to helping the organization and supporting my role as well. I know he misses "hands-on" medicine, but his contributions to JDRE are vital. He has, over the years, provided the organization with informed medical experience, coupled with the overall brain power resting beneath that lush, curly, black hair I found so attractive 24 years ago. Not bad now, either.

In 1989, Robert was appointed to the JDRE International Board to the seat vacated when David Dinkins was elected mayor of New York City. (An aside: Mayor Dinkins, in 1983, when he was city clerk, issued the marriage license that

allowed me to add the Levine to Mary Tyler Moore. But wait, let's be honest here, my true name is Mary Tyler Moore Meeker Tinker Levine.)

We launched our first major donor initiative, The Only Remedy Is a Cure campaign, in 1990. We were unsure if we could raise \$100 million in 10 years. Of course we did it in less than five.

Then in 1995, on the occasion of JDRE's 25th anniversary, we took stock of our progress and frustrations. And we recog-

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nized that even with all the basic science progress that had been made, there was a major gap that was not going to be filled by anyone other than us—the need to focus much greater resources and efforts on moving scientific advances from the laboratory bench to the bedsides of our loved ones with diabetes.

So we re-doubled our own fundraising efforts, hired our first professional research staff, developed a roadmap of how research could get us to our cure goals, and launched a very aggressive government relations program. The results have been extraordinary—billions of new dollars for diabetes research; hundreds of millions of dollars for stem cell research; and significant breakthroughs in type 1 genetics, drug discovery, device development, and clinical trials. Breakthroughs that show real promise in the areas of islet replacement, beta cell regeneration, closed-loop artificial pancreas development, prevention and treatment of complications, and prevention of type 1 in the first place.

These are accomplishments that naysayers repeatedly warned us could not be done (but we didn't listen). More important, these real accomplishments (gifts JDRE has given me and everyone with type 1) were the necessary stage-setters for what must come next.

And what is "next?" In the next five years, we will be raising the dollars necessary to fund \$1 billion for cure-related therapeutics.

To celebrate my 23 years of service as international chairman of the Juvenile Diabetes Research Foundation, in November 2007, at a formal ball, I accepted a check in the amount of \$23 million dollars to honor those 23 years. It will further attract more money in my name for research.

The campaign is called "Forever Moore." Contributions have come from chapters everywhere with gracious nods from business, individuals, and corporations to encourage the furtherance of "Bench to Bedside" science. I'm tired of curing diabetes in mice. We need to see more relevant statistics from and for humans. The mice will have to wait. It's long been a prayer of mine to reduce animal work and move on human experimentation.

It's difficult to express my awe at receiving this enormous honor. To this day, I'm slightly surprised when I'm recognized in public, and a kind word regarding my work is always lovely to hear, but causes me to question, just a little, the qualifications of my admirer.

So to be acknowledged at this level is as difficult to grasp as is the image of my father with a grin of pride on his face.

But, you know what? In my second go at growing up, I'm learning that I can love this man and forgive him for being less than perfect. Though our roads have taken us to very different places, I can see similar strengths that have guided us: duty, loyalty, compassion—all standards that have made me a good person.

So I dedicate this honor to you, Dad, in the hope that it makes you smile as you say, "Well done, chum." ●