

PHIL SOUTHERLAND and JOHN HANC

**NOT  
DEAD  
YET**

MY RACE AGAINST TYPE 1 DIABETES  
FROM DIAGNOSIS TO DOMINANCE

Thomas Dunne Books

St. Martin's Press  New York

## A Man from the South

Well it's way, way down where the cane grows tall

Down where they say "Y'all"

Walk on in with that Southern drawl

'Cause that's what I like about the South.

—ANDY RAZAF

My name is Phil Southerland. While it's pronounced "Sutherland," the spelling of my surname reveals something about who I really am: a man from the South. I was born in the South, raised in the South, went to college in the South, and still live in the South. You can tell, as a "y'all" or two still manages to creep into my speech.

I've learned from traveling that a lot of people tend to assume that because you are from the South, sound like it, and, in my case, have a name that practically advertises that fact, it stands to reason that you must be a redneck or a right-wing gun nut. I'm none of these. There is not a Confederate flag decal on my bike or a gun rack on my car. I'm not a reactionary or a racist. And I don't get all misty-eyed about the Lost Cause of the Confederacy. Heck, I'm not even that interested in the Civil War, even though I'm pretty sure a few of my ancestors fought in it.

While there are southerners who conform to that stereotype,

most of the good people I know from south of the Mason-Dixon line are not like that. I have, however, retained some of what I'd like to think are ennobling and civilized attitudes and conventions of being a southerner. I say "please" and "thank you" a lot and call people I meet "ma'am" or "sir." I do hold doors open for women.

Other southern attitudes have both helped and, maybe, hindered me on my journey. In business, I tend to be a man of my word, and I do believe that there is such a thing as one's "honor" and that it needs to be preserved. On the other hand, I'm pretty stubborn, especially if I think you're forcing me to do something that I don't perceive as right or fair. That's a southern "thing," by the way. I know a few folks down here who would even say that's why we fought that war, but I digress.

My part of the South is a place called Tallahassee, Florida. Yes, Florida. A genuine southern state that has been usurped by snowbirds, Yankees, retirees, tourists, millionaires, and Cuban émigrés. I'm kidding, but really, my Florida has about as much in common with *that* Florida—the Florida of Disney World, South Beach, and Fort Lauderdale—as I do with Gloria Estefan. That part of the state, amazing as it is, in many ways, and as much as I enjoy visiting it, is a long way in every sense from the Florida I'm from. In the Sunshine State, the farther north you go, the more southern you get. In its mind-set as well as miles, Tallahassee is closer to Valdosta, Georgia than to Vero Beach. "Visitors are struck by how southern the city seems," according to one guidebook to what is often called Florida's Great Northwest. "Unlike the more populous parts of the state, Tallahassee is a place where time seems to slow down a bit. People are more easygoing here than in, say, Miami or Tampa. There is an almost genteel sensibility in the air, one that captures the best aspects of southern tradition."

I think they were right on about that. Talk about tradition.

Heck, the name Tallahassee itself means “Old Town,” and indeed it was already an old Apalachee Indian town by the time Hernando de Soto arrived here in the winter of 1539–40. The Spanish built missions here, and a new tribe of Indians, the feared Creeks, settled here in the 1700s, before their settlements were burned by Andrew Jackson during the Creek Wars of the early 1800s. In 1824, the Old Town was chosen as a compromise site for the capital of the new state of Florida. Why? Because it was midway between the Ochlockonee and Suwannee rivers; and midway between the two established towns of St. Augustine and Pensacola. Tallahassee, located at the narrowest point in that part of Florida, became the compromise—and a somewhat unlikely choice for a state capital, located far from any major river or sea. Yet, that decision affected me and everyone else who would grow up there in the subsequent 185 years—because, although it would maintain its southern gentility and despite its location in the middle of nowhere, Tallahassee became a locus of power, influence, and, most important to me, learning. When it comes to higher education, Tallahassee is to Florida what Boston is to Massachusetts. We have two excellent universities and a community college and, when I was growing up, a quality public and private educational system in which there was one teacher for every twenty students, and nearly 65 percent of high school graduates went on to college or technical school.

So you shouldn't be fooled by the fact that we eat grits and say “sir” and “ma'am” or even by the city's name, which can be rolled off the southern tongue, molasseslike: “Tahhhl-a-hahhh-see.” The truth is that, although the pace may be slow, this was, starting back in the 1980s, a shining example of what people were calling the “New South”; a young city, a smart city, and so, not surprisingly, the place where a smart, young couple named Harold and Joanna Southerland settled down in 1980.

Joanna was like many of those who ended up in the Sun Belt in that period. Her native name was Hagan, and she was no mint-julep-sipping southern belle. Born in Philadelphia, she had moved to St. Petersburg, Florida at age five. Her dad, my maternal grandfather, was a World War II vet—he had served in the navy—and had hoped to make it big in the postwar Florida real estate boom, following in the footsteps of his father-in-law. But he never really did. A kind and gentle man whom I vaguely remember, my grandfather did impart an important lesson to my mom that she passed along to me.

“Whatever you do in life,” he told my mom, in one gut-wrenchingly pained and honest moment, “for God sakes make sure it makes you happy.”

Clearly, what he had done, with moderate success, had been paid for with the price of a miserable life. My mom initially interpreted her father’s message as “have fun.” Which she apparently did at college in the late 1960s. But when she graduated, she ended up finding a job in the most unlikely of places for someone of her independent spirit and liberal views: a steel company. This was pretty funny for a woman who had by her own admission partied her way through four years at the University of South Florida, then traveled for an extended postgraduate European hippie trek, returning to the United States with exactly twenty-five cents in her pocket.

But attractive, young, college-educated women were in demand in the business world in those new ERA-conscious 1970s. Joanna worked for a succession of major steel corporations, traveling to Europe and Japan on sales and marketing calls. She would return periodically to Florida to visit her family and friends, including one who had moved to Tallahassee—which my South Florida snob-mom dismissed as “a redneck southern town” (yes, just as those

who were born in northern Florida are proud of its southern leanings, so the folks in South Florida look down when they look upstate).

In Tallahassee, a young Florida State law-school professor lived next door to my mom's friend. One day in 1978, he and Joanna started chatting. "He knew all about Flannery O'Connor and I was impressed," she recalled. "At the time, I was hanging out with guys from the steel industry and all they knew about was Budweiser." This guy was also a marathon runner, caught up in the 1970s running boom, which was then reverberating across the nation. Distance runners were cool and sexy and mostly male back then; and Joanna was impressed. And unlike Joanna, this gentleman was from a family whose southern roots were as deep as those of magnolia trees, as was evidenced by the young man's almost comically archaic name: Harold Philpott Southerland, Jr.

He couldn't stand "Harold," and of course no one, not even someone from the Old South, could go around in the late twentieth century with a name like Philpott, so he was called Phil. (Philpott, by the way, wasn't really a first name at all, but rather the family name of his paternal grandmother.) Phil Southerland, my dad, grew up in Huntsville, South Carolina. He attended West Point, did his mandatory service hitch just before Vietnam heated up, and then attended law school at the University of Wisconsin. After graduation, he went to work for a conservative Milwaukee law firm, but he got the boot when he started defending draft dodgers. Looking back, you have to admire his chutzpah. A West Point-educated lawyer defending draft dodgers! It revealed an independent, nonconformist streak combined with the time-honored southern virtue of doing what you felt was the right thing, even if it wasn't necessarily the best career move. From there Phil went where really bright mavericks often go: academia. He took a teaching

job at Florida State University's College of Law, which is how he ended up in Tallahassee, charming—with his intelligence, good looks, and reading list—a pretty, young lass sixteen years his junior.

Joanna wasn't the only one impressed by Phil. "He was the kind of professor students loved," she recalled. "Eccentric, brilliant."

And, as it turned out, an alcoholic, whose condition started with a couple of drinks before dinner and got progressively worse. To his credit, my dad would later address his alcohol problem and beat it—as daunting an achievement as anything I would ever face. But in those early years, his manic personality drove Mom crazy. It wasn't only the drinking; as she tells it, he was a man of extremes, often swinging wildly from one end of the spectrum to the other. He stopped marathon running, for example, and instead took up . . . chain-smoking. I guess it didn't help things when I came along. Because what happened then was enough to drive any parent to drink.

I was born on January 15, 1982. From early on in my life, they talked about my baby-blue eyes. They still do. But Joanna saw through that.

Even though I was her first child, Joanna sensed within a few months that there was something wrong: her baby wasn't eating, he was losing weight, and his diapers were always soaked.

Joanna was confident; a bit high-strung and nervous sometimes, concerned about the man she had married, maybe; but sharp-witted and strong. Nonetheless, she was scared. She took me to the pediatrician.

There was something wrong, she insisted.

Nothing wrong, the young pediatrician replied.

“Then why is he losing weight?” she asked, after one week in which I’d lost three pounds.

“Sometimes they do that,” he replied.

The situation worsened over the summer. At one point, I started nursing constantly. Joanna called the doctor. “He’s probably teething,” was the response.

Two nights later, she took me back to him to find out why my breath smelled fruity. He really had no answer.

But over that weekend in August 1982, I began to pant. A horrible sound that made it seem like I was running out of life, already. And for one terrible moment, when Joanna went to attend me, I looked up at her with bright blue eyes—eyes that had only just begun to fix their gaze on the still-new world around them. Those eyes were starting to turn a cold gray—and behind them was an unarticulated but unmistakable cry for help.

She looked into those eyes and saw death. Horrified, she alerted Phil and called the emergency room. “It’s probably a flu,” said the physician on the other end. “Bring him in.”

As they scooped me up, Joanna made one more call: to the pediatrician. “You said it was nothing,” she said between sobs. “Well, I’m taking him into the emergency room. You can be there or not.”

And with that she wrapped me up and rushed me off to the hospital. There, I was examined. My weight was fourteen pounds, down from twenty-four just a week earlier. I was dehydrated, they said, and put me on a glucose IV—as it turned out later, that was the worst thing that they could possibly have done to me. Within minutes, as Joanna hovered over my bed helplessly, I grew limp and still and began to emit a sickening wheeze. “A death rattle,” she recalls today (and believe me, it’s scary to hear about this kind of stuff happening to any little baby, but especially when that little

baby was you). Panicked, she ran into the hall, calling for help. Orderlies, nurses, and a doctor came rushing in and hovered around the child's bed. "Is he going to die? Can somebody tell me, is he going to die?" cried my mom.

No one could tell her.

They were trying different things. She saw what appeared to be an uncoordinated symphony of hands poking, sticking, and pricking me with various instruments. But again her mother's intuition sensed what they couldn't, almost as if I had sent out a distress signal directly to her. "He was going fast," she recalled. "I could feel it . . . he was dying."

At that point, she was politely but firmly ushered from the room. Never a religious person, Joanna then did what most non-believers do in a life-or-death crisis: she asked for forgiveness and began to pray. They say there are no atheists in foxholes or emergency rooms.

She still remembers it vividly. "It was dusk, and I will never forget the lighting," she told me. "The sun setting behind the steel bars of the pediatric baby bed." It must have appeared as the sun setting on my life. For the next two hours, my father sat in a chair, squeezing the arms until his knuckles were white. Joanna paced so much that the young nurse finally told her she'd be better off if she just tried to sit still. She left, went downstairs, and called her priest.

Joanna was raised a good Catholic girl. Like many of her generation, she had strayed, finding the church too restrictive and in some ways sexist. Now, she wanted to call on the power of the almighty, but at the same time, my mom—bright, rebellious, independent, and now heartbroken—could not rationalize it. Why ask the Lord to save me when he was killing me?

"Why does God do this to a baby?" she cried into the phone.

“Why not a mass murderer . . . someone who deserves it? Or why not me . . . or his dad . . . why an innocent baby?”

He probably gave an answer. But not one that made any sense to her or eased her suffering. As far as she recalls today, “The priest had no answer.”

That was the end of her Catholicism.

Two hours passed in a blur. The doctor came in—not the young, self-confident doctor but an old, courtly southern physician. She remembers it was late afternoon when this happened. There were autumn shadows peeking through the half-drawn blinds of the little waiting room. The late-afternoon sky was a pinkish color, an apt metaphor for what she sensed was the darkening of her own life, a life that she was sure would be spent forever lamenting the loss of her firstborn.

The doctor spoke. “I’ve got good news and bad news,” he said.

She braced herself. After what seemed an eternal pause, he continued. “The good news is that he’s going to live.” Joanna didn’t care about the bad news, initially so overjoyed by the surprising report that she began to weep. She barely heard the rest of what he had to say.

“. . . But he has diabetes. The youngest case of juvenile diabetes we’ve ever seen.”

*Diabetes*, she remembers thinking. *Something about sugar and insulin. Injections, right?* No candy bars for her son, she supposed. Regrettable, sure, but he was going to live. Thank God. Then, the other shoe fell. There was more bad news, delivered not that day but a few days later, once a specialist had been called in. He was blunt in his assessment: “The statistics on children with juvenile diabetes this young are grim.” Based on then-current care and technology, he predicted that “after twenty-five years, he’ll probably be blind and suffer kidney failure—that is, if he’s still alive by then.”

The dour prospects were based on a scientific truth: high blood glucose levels can end up killing certain cells in the eyes and kidneys, which is why diabetes is the leading cause of adult blindness and of kidney failure. Still this was some prognosis for a young mother to hear about her baby.

Sightless, on dialysis, in all probability dead by twenty-five.

She listened, her jaw set. This time, her reaction wasn't tears. It was quiet, simmering anger, a steely resolve. Her baby boy had survived. And just as surely as she had thought he was about to die that Sunday afternoon in the hospital, she was now equally sure that he would live and continue to live. The maternal instinct that had told her there was something wrong with her child, despite what the first doctor had said, was now channeled into determination to prove this specialist wrong. "Dead by twenty-five, eh?" she said. *Not if I have anything to say about it!* You don't, was the response; there's not much you can do. *Oh yes there is*, she said to herself, driving home that afternoon with her baby. *Oh yes there is. There are days and months and years of things I can do. There are books to be read, opinions to be gathered, lists to be made, friends and neighbors to be mobilized. There are things we can do.* Exactly what, she wasn't quite sure at that moment, but she would figure it out. She drove home that afternoon through the rows of cypress trees, past the stately homes and the bustling college campus; back to that "redneck southern town" of Tallahassee, Florida. A town whose merits she would soon be forced to reconsider, for the better.

She looked around at the campus, the hills, the trees, the houses. Her son would live to experience this, she vowed to herself. All of it. Diabetes or no diabetes. I owe her my life for that.

Let me tell you a little bit about the disease that affects me and about 25 million others in the United States alone.

My problem starts with my pancreas, a cone-shaped organ most of us probably couldn't even locate on an anatomy chart. Even more specifically, my troubles began in an area of the pancreas that has one of the most colorful and imaginative names of any part of the human anatomy: the far-flung "islets of Langerhans," which sounds like someplace that Frodo and his friends would have visited in their quest for the Lord of the Rings. Named after the German scientist Paul Langerhans, who discovered them in 1869, it is really a clever appellation for a cluster of about ten thousand cells located in the tail of the pancreas. Amid these cell clusters are beta cells, which function as the microscopic factories that produce insulin—a key hormone in the metabolism of glucose.

Insulin is important because it allows glucose to move from the bloodstream into body's cells to be used for energy. People with type 1 diabetes are their own worst enemies. For reasons that we don't understand, my body's immune system has attacked and destroyed its own insulin-producing beta cells, resulting in dangerously high levels of blood glucose.

This is the "sugar" part of diabetes you've probably heard about. It's interesting how they first figured this out. Centuries ago, they used to take the urine of someone suspected to have the disease and pour it on an anthill. If the ants flocked to it, they knew there was sugar in the urine. In the eighteenth century, the Latin term *mellitus* was added to "diabetes," referring to the sugary taste. But it wasn't until a century later, in 1889, that two German scientists discovered that the pancreas was involved with diabetes. As part of an experiment they removed the pancreas from a dog and found that afterward it urinated again and again. They tested the dog's urine for glucose and discovered that it had developed diabetes—because of the removal of its pancreas.

Something in the pancreas prevented most people from having diabetes. But what? For the next few decades scientists tried to find this magic substance. In the meantime, people tried all kinds of methods to keep diabetics alive. None worked, especially with juvenile diabetics. No doubt, had I been born sixty or seventy years earlier, I most likely would have died, just as the doctor had predicted to my mom. In 1921, a young Canadian doctor named Frederick Banting, fresh out of med school, had an idea. He suspected that cells in the islets of Langerhans played a role; that something in the cells of the islets (or “isles” as they’re also called) secreted a substance that was the key to diabetes. He was right—that substance was insulin. Working in the lab of Professor J. R. R. MacLeod at the University of Toronto, Banting was able to isolate it and, with the help of a biochemist, purify and then inject it into a fourteen-year-old boy dying of diabetes. Although already weakened by years of the disease, the young man survived, and with regular injection shots lived for fifteen more years, until he died of pneumonia.

At last, diabetics had hope: something could keep them alive.

In 1923, Banting and MacLeod were awarded the Nobel Prize in Medicine for their discovery of the role of insulin in treating diabetes. (Wanting to give credit where credit was due, the two of them shared the prize with the biochemist, which was a pretty stand-up move, don’t you think?)

In the years since, treatment for diabetes has continued to improve. The incidence of the disease, however, has reached epidemic proportions. Here we have to make a distinction: my disease comes in two types. You could call it Diabetes Classic and New Diabetes, and that might be funny, if it weren’t for the fact that the rise in the new form has been truly alarming and, unlike my type, largely preventable.

According to the American Diabetes Association, my kind of diabetes—type 1, or juvenile diabetes, which results from the body's failure to produce insulin—accounts for only 5 to 10 percent of the cases diagnosed. The vast majority, and this is where the big increases have come, are type 2—the so-called adult onset diabetes; a form of the disease in which insulin resistance, not deficiency, is the problem. Type 2 is often lifestyle related, with obesity being a big factor.

The ADA estimates that there are now 23.6 million people in the United States with diabetes. That's almost 8 percent of the total population of the country! And it's growing: more than a million new cases are diagnosed each year, most of them type 2. The good news is that the prognosis for children diagnosed with type 1, even at very young ages, has vastly improved in the past decade. A 2006 study in Sweden tracked type 1 children over a period of years and found that not a single child developed end stage renal disease, which is what frequently ended up killing people with type 1 in the past. "That's profound," says Jeff Hitchcock of the organization Children With Diabetes. "It means that our kids will die *with* diabetes, not *of* it." (And when Hitchcock says "our kids," he means it. His daughter Samantha was diagnosed with type 1 at age two and is twenty-three at this writing, and healthy.)

That is a sea change. Meeting the kids that I do at diabetes camps every summer, knowing they can all have a future; a real future, and become whatever they want to be, fills me with joy. It's a far cry from what my mom was facing. Remember, when Joanna was getting the news about me, it was 1982 not 2010 and while things had already changed since the days when a diagnosis of juvenile diabetes was close to a death sentence, there were still no guarantees; and few of the physicians she went to were talking about me having anything resembling a "normal" life. The best that could be expected is that I would survive, not really live. A life of

injections and restricted activity; a life limited by a cluster of malfunctioning pancreatic cells.

My mom learned all this in the weeks and months after I was born. Remember, the average age for diagnosis of type 1 diabetes is fourteen. I was seven months old when they figured out that I was diabetic—one of the youngest cases ever diagnosed. Of course, had I been born a few decades earlier, I would have had no chance. But even in the 1980s, when diabetes treatment was already well understood, my odds for living a long and healthy life weren't great. (Losing one's sight is still a concern for diabetics: the ADA estimates that the disease is the cause of twelve thousand to twenty-four thousand cases of blindness each year.)

That was the future Joanna was being asked to accept: your baby boy, quite likely blind and quite possibly dead by twenty-five.

Once she had recovered from the shock, once she was done with the “why me, why my baby?” stage, Joanna got ready to fight back. She knew that diabetes could be managed—meaning that by proper attention to diet and monitoring and taking injections, you could increase the odds of survival and good health. She resolved to do everything she could to manage my diabetes by making my childhood as “normal” as any childhood could be. I wasn't going to get singled out, treated like easily breakable china, or quarantined. Yes, there would have to be changes and modifications in the way we did things. But Joanna wasn't going to let diabetes stop us from being a family or me from being a kid.

Here, what she had originally dismissed as that “redneck southern town” of Tallahassee became important. Our neighborhood, in the Piedmont Park section of the city, was composed of mostly white-collar families, and many of them worked at nearby Florida State University. It was a fairly cohesive place in the early 1980s; not like the Sun Belt suburbs I see today, where so many peo-

ple are transplants and nobody really knows anyone else. Many of the people we knew had come from somewhere else even then, but we knew them, they knew us, and when news got around that Joanna Southerland's baby was diabetic, they were ready to help.

Believe me, my mom didn't waste any time in taking them up on it.

"Some people are afraid of asking for help," she says. "I'm not."

Joanna drove all over the state, to clinics, symposia, to diabetes-management centers, and made herself an expert on my condition. She went to neighbors and talked to them about the disease. She wanted them to know what was going on if they ever saw an ambulance at our house. And particularly, to those with other small children, she wanted them to know what to do in case I ever had a seizure.

It's interesting how a diagnosis like this affects parents.

My mother got mad, then got motivated, educated, and went on to mobilize the neighborhood.

My father tried to do his best, and as a capable, intelligent man, his best can be pretty good—but not at that point in his life. My diagnosis sent him into a spiral, and he would soon hit rock bottom.

About eighteen months after I was born, my mother took me to the University of South Florida in Tampa, where they had a good pediatric endocrinology unit. Here were physicians who knew kids and knew diabetes.

We spent the day there, as they examined me and did a battery of tests. I think it was a bit of a test for my mom, too—one she intended to ace. She'd already started marshaling her resources to combat this disease. She was staying up nights to monitor my blood sugar. Giving me shots. Organizing my diet and treatment.

She was determined to prove wrong the doctor who had predicted blindness and kidney failure. She was determined to show these guys—the hotshots at USF—that she was a mom who was on the ball and was doing everything humanly possible to ensure that her son was going to live a long, healthy life, despite the early diagnosis of type 1.

She succeeded. At the end of the tests that day, the head physician reviewed the paperwork and looked up at my mom. “He’s doing really well,” he said. “You couldn’t be doing any better than you are now.” Joanna beamed as the older doctor shook her hand, then left the room. My mom said she was ready to celebrate, ready to give herself a slap on the back, when she noticed that a second doctor, a younger man, who was doing his residency or internship at the hospital, had remained behind. “He’s right,” said the younger physician. “Your son’s doing fine.” He paused. “But you’re going to have a nervous breakdown.”

As my mom recalls, she immediately crumbled into tears. “I know,” she said, through the sobs. “My husband’s an alcoholic.”

There it was, out in the open, admitted to a stranger no less. My father, the brilliant, charismatic, idealistic, well-read law professor was an out-of-control drunk.

Joanna knew it, but she was so wrapped up in caring for me that she hadn’t really faced the issue. But it was clear that father Phil was going down. A few months after I was born, he lost his license and had to take the bus to the university every day. Another time, my mom got a call from her friend and neighbor Iris Yetter. Iris had been driving down our street when she saw me running around the driveway in my diapers, unattended. She stopped, got me safely back into the house, and immediately called my mom. Joanna was furious. I was supposed to have been watched by my dad

that day. But he was inside the house, drunk, and I had managed to get out. Good thing I didn't go toddling into the street.

Joanna finally confronted him. She recalls standing in the driveway the morning we left for Tampa, pleading with my dad to stay sober while we were gone—as if he were a frat boy who had a tendency to down a few too many. “Please, don't drink,” she recalls saying to him. “Kind of a ridiculous request, I realize now. But at the time I had no idea how bad his problem was.”

We found out later how bad. No sooner had my dad sworn to his wife that he wouldn't drink while she was away, having her diabetic son examined in a hospital, than he walked up to the liquor store with a briefcase, which he proceeded to fill with bottles of vodka. He was lugging this briefcase of booze home when a neighbor spotted him walking, picked him up, and drove him home. The neighbor (who later relayed this to Joanna) noticed the bottles sticking out of his bag. I'm not sure what my dad was thinking—that somehow his lawyer's briefcase would provide immunity for the Stolli bottles peaking out the top? The answer is that in his state, he probably *wasn't* thinking.

At about this time, several hundred miles away, my mom was hearing the words of truth spoken to her by the resident.

According to Joanna, when she started crying, admitting to the young doctor that her husband was an alcoholic, he went on to speak to her directly and in no uncertain terms.

“Then you're just going to have to leave him. You cannot take care of a diabetic and a drunk.”

Obviously, no physician today would step over the boundaries of medicine to family counseling, for fear of lawsuits by patients or censure by some medical board. But my mom swears that this is exactly what he said to her. “I'll never forget it,” she says of this day.

“I realized that this stranger . . . the young physician . . . was right. I had given up my career. I was totally dependent on this man for finances and for the well-being of myself and our child and he was out of control.”

The whole thing with this young doctor seems a mystery to me. She had never seen this man before, and efforts to reach and thank him later were fruitless. No one at the medical center seemed to know who he was. If I didn't know my mom better, if I didn't know that she values truth and honesty and accuracy, I would swear that she imagined the whole thing. But I know she didn't, which is what makes it so strange. It seemed almost as if this physician had been inserted as a plot device in her life, like a playwright deciding that a Greek chorus was needed at this very point to help the audience better grasp a character's motives, or to move the story along.

Which it most certainly did, because instead of driving back to Tallahassee, Joanna decided instead that we were going to my grandparents' house in St. Petersburg. There, she would deliver a long-distance ultimatum to my father. My grandmother—Joanna's mom—was happy to see us. Because she had always been suspicious about my dad's drinking, and sensed that there was more of a problem than anyone was admitting, she fully endorsed what my mom did that night.

Joanna called my dad and said, “I'm not coming home unless you quit drinking.”

At this, my dad went off on a real bender. The way I heard it, he got into the shower . . . why the shower I'm not sure . . . and proceeded to drink until he was comatose. My mom, concerned that before long I wouldn't have a father, called a friend who had once been a drinking buddy of my dad's and was now in Alcoholics Anonymous. This fellow was on his way to Europe on business, but he promised my mom that he would get someone over to our

house in Tally to help my dad. He did, and they managed to get my dad into a detox center. From there, he went into Alcoholics Anonymous.

So, something positive did come out of this whole awful chapter in our lives. My dad would survive and make a pretty incredible turnaround as he successfully fought his addiction, becoming clean and sober from that point on.

The relationship between my mom and dad was doomed, however, although it would take two more miserable years to finally end.

My dad became immersed in AA. Joanna went to meetings, too, but before long, as she says, “I was Big Book-ed out,” referring to the tome that folks in AA read for inspiration and to help keep them from succumbing to temptation. While my mom was home taking care of me, my dad met a woman in his meetings. She, too, was struggling with alcohol, and I guess he felt that she was someone he could connect with better. Before long, as I saw it through young eyes, he started to be around less and less. And when he was, I remember some screaming-bloody-murder arguments between him and my mom.

At some point, probably when I was four or five, Phil Sr. decided to leave Joanna permanently. According to my mom, when he left, he cleaned out all the bank accounts, leaving her with twenty-five dollars. Not even enough to buy insulin for me. One of our wealthier friends heard about it and got so incensed that she told Joanna to go out and hire the nastiest divorce lawyer in Tallahassee, and she would pick up the tab. Joanna did just that. The hotshot lawyer turned out to be a “she”—somewhat unusual in mid-1980s Florida—who immediately filed an emergency motion for support. The lawyer laid out the case, described my illness and how my mom had put aside her own career to devote her full time to raising a

diabetic son. The judge awarded Joanna about three-quarters of Dad's salary, so at least she could keep a roof over our heads and insulin in my veins.

One Phil Southerland was now out of the picture. Between diabetes and divorce, the other Phil Southerland was going to have to grow up fast.

## My Type of Childhood

The team is led by world-class cyclist Phil Southerland, who was diagnosed with Type 1 diabetes at 7 months old. Mr. Southerland has been a trailblazer for people with diabetes and hopes to do for diabetes care and prevention what cyclist Lance Armstrong has done for cancer.

—THE NEW YORK TIMES

Long before I ever heard of Lance, I loved *Arthur*.

You know, *Arthur*, the long-running animated kid's show featuring an aardvark with glasses.

I have this vague memory from when I was about six years of age. I'm in my mom's bed, it's afternoon, I'm watching *Arthur* on TV, and then I have this pain in my stomach. Terrible pain. I have to rush to the bathroom. I throw up. I'm lying on the floor by the toilet in a fetal position, crying and holding my stomach. My mom is shoving a glass toward me, saying, "You have to drink something." And I'm saying, "No, I don't wanna."

Then the ominous words: "If you don't eat or drink anything, we're going to have to do the suppository."

That's a threat certain to get your attention, even if you're six

years old and can't spell *suppository*. What's being said is, basically, Do this, or we're going to shove a pill up your behind.

The bed-TV-bathroom-puke cycle. This was, according to my mom and my own recollections, pretty much a regular event, from the time I was a toddler until I was about ten or eleven. Every kid gets a cold or flu. But when I got them, things could get serious very quickly. When I got sick from the flu, I vomited. The more I vomited, the less I ate. The less I ate, the lower my blood sugar got. The lower the blood sugar, the greater the danger of hypoglycemia, and my ending up in the ER.

There, I knew, lurked my other great enemy. It wasn't the hospital itself I was afraid of, since I'd probably spent enough time in them already at that point in my life. It was the IV needle. Now, keep in mind that I was no stranger to sharp objects as I had one breaking into my skin four times a day. Diabetics require insulin: my schedule was a shot in the morning, when I woke up; at one in the afternoon, when I came home from school; a third shot at 6:00 P.M.; one more at bedtime.

At first it was unpleasant for me, as it is for most kids. At about age four, I staged an early protest against the inequity of it all, running out of our house and hiding behind a neighbor's house to avoid having a shot. My dad, still in the picture at that point, was unmoved. He came out, found me, dragged me home, and gave me the belt. That was Old South-style child rearing—no doubt the way he and generations of Southerland kids had been brought up. I guess it worked, though, because aside from that one moment of push-back, I took to giving myself injections without too many problems. Here, Dad got credit—it was one of his only contributions to the management of my disease at that point my life, but a very significant one. He had another, more patient side and he showed it when he trained me how to give myself shots. We'd prac-

tice using saline. He'd say, "Give me six units." I'd draw up six units. He'd check it. Then I'd dab the alcohol on his skin like he'd shown me, pinch the skin, and inject him. He'd never flinch—even though it must have stung. He was teaching me a skill that I'd need to stay alive, but it was also his way of saying, "See, it's not too bad."

It worked, as I remember a great sense of accomplishment the first time I injected myself. I was probably about five years old at the time. I was in my room, it was time for my shot, and I said, "All right, I'm going to do it the way we practiced it." So I gave myself the injection, and started jumping around the house, "Whoo-hoo! I did my own shot!" My mom was alarmed. "How much insulin did you take?" she asked nervously. I told her not to worry. I knew I'd done it correctly. I also knew that from that point on, I'd be giving myself my shots. It was like the first time riding your bike without training wheels—a big step on the road to independence. Soon, it really didn't seem like a big deal, at all. A small needle, maybe a 12-millimeter-long syringe, pop, and you're done.

That didn't mean I was accepting my disease completely. About a year later, when I was six, I was at a birthday party for one of my little friends, and I asked my mom for cake.

"Sure," she said. "Just do your shot first."

"I don't wanna do my shot. I just want the cake."

"Fine. You'll go blind."

"Huh?"

"Don't do your shot, don't take of yourself, you'll be blind by age twenty-two."

That got my attention. While to a six-year-old the age of twenty-two seems like a far-off distant time, I was still old enough to be scared by the idea of blindness.

“Okay,” I relented. “Can I have my shot, Mom?”

“Nope.”

“Why not?”

“Because you’re ungrateful. And if you stay that way, you’ll be blind by the time you graduate college.”

“Okay, I promise! I promise I’ll do my shots! I promise I’ll take care of myself!”

I don’t remember the piece of cake, although I’m sure I enjoyed it. I do remember the impact of my mom’s shrewdness. She got my attention, all right. It was a lesson I didn’t forget. From about that point on, I took my own shots, and took them faithfully without ever causing a problem. At six years old, I became the CEO of my body.

That IV needle was a different matter altogether. The thing looked like a drill, like one you would see pulverizing concrete during road repairs, except I imagined it boring down into my skin, tearing through tissue and bone, and coming out the other side of my arm. Of course, that never happened, but that’s what it looked and felt like in my young mind’s eye. The mere sight of that IV needle would always bring tears to my eyes. Mom would say “bite my finger” while they hooked it up. I’d bite so hard, I’d draw blood. So there we were, having blood drawn together. Mine from a giant needle, hers from my little sharp teeth.

One of the little-talked-about side effects of diabetes is the insidious effect it has on the family, how it can erode the bonds among parents and children. Between the parents, it’s often the blame game. Because in some cases (although not all) there’s a genetic predisposition to the disease, there’s a lot of “it’s your fault . . . it came from your side of the family!” kind of reaction. Or, if not the genes, it’s the way the disease is being managed. Somebody’s not doing enough to make sure the child is following the diet; not

vigilant enough; not on top of the insulin shots. Blame, blame, blame. Someone's always to blame. As I said, I'm sure the burden of being father to a diabetic child was part of what split my mom and dad apart. But there were plenty of problems there before I even came along. Plus, you pour alcohol on the whole situation, and it's ready to catch fire. Which it did.

By the time I was in elementary school, my father was not around on a day-to-day basis. So the family dynamic was Mom, my brother, Jack, and I. For siblings, the diabetes dynamic can be even worse. The siblings without diabetes see all this attention, all this care being paid to the sibling who has the disease. The kid without begins to wonder: nobody is scurrying around *me*, worrying about every fluctuation in *my* health, every morsel *I* put in my mouth. So in the child's mind it appears as favoritism. That's very typical. To his credit, Jack, four years younger than I, was never jealous—or at least never articulated any jealousy to me or Mom.

He had good reason to get frustrated. There was the time I got the flu—it was another one of those bed-TV-bathroom-puke deals, except it was Christmas Eve. I ended up having to stay overnight and spend Christmas Day in the hospital. My mom wouldn't open gifts on Christmas morning at home because she knew I was lying in a bed in the hospital. So Jack, who was probably four or five years old at the time—peak age for Christmas excitement!—had to wait all day until he could open his gifts; and then he had to do it in the hospital. The kid never complained, and I've always been impressed by that.

Then, there was the time I had a seizure.

Every diabetic lives in fear of seizure—it's what can kill you. These attacks occur when there's not enough sugar in your blood to feed the brain. This typically occurs when you take too much

insulin. When I was growing up, there were two types of basal insulin (meaning that it's constantly there, working, mimicking your metabolism): One went by the brand name NPH. I used the other one, called Lente. You didn't really have to worry about it. Unless, of course, you were a growing boy or girl and your metabolism started to change and your body mass was increasing. Most of that happens when you're sleeping, a time when your blood sugar isn't likely to be monitored. So, suddenly, through no one's fault, the amount of insulin you were giving yourself is inadequate, because your metabolism is changing . . . literally overnight. Remember, insulin essentially takes sugar out of the bloodstream. If the insulin starts taking out too much blood sugar—which it would do when your body was changing—then you'd have a seizure. The first response when that happens is to give the diabetic glucagon, a hormone that causes the liver to release glycogen, which raises blood sugar. To give a glucagon shot, you mix saline into it and then inject it into the patient. So this one time I'm sitting there having a seizure, my mom's calling 911, and little Jack rushes to the refrigerator determined to help. He injects me with saline, forgets to mix in the powder. My mother freaked because without the glucagon, the saline would do nothing, and in a seizure every second counts. So here's a five-year-old trying to help and now he's wondering if he just killed his brother. I can't imagine being in his shoes. Imagine how he felt for that moment: *I might have just killed my brother*. Obviously, he didn't, and the paramedics arrived and gave me glucagon. But what kid should have to go through this?

Jack has had his own problems over the years. In my own way—which is often not very compassionate or gentle, I admit—I've tried to help him. But one thing I sincerely hope is that his experiences living in that house, with a diabetic brother and a mother

determined to make his life normal, did not inadvertently affect Jack's sense of normalcy. In other words, if he's screwed up (and who of us aren't at one point or another in our lives?), I hope my disease didn't contribute to it. Because he doesn't deserve that. One kid in the family getting his life turned upside down by diabetes is quite enough, don't you think?

At this point you might also be thinking that my childhood was a horror. Puking, injections, seizures, suppositories, divorce, and sibling guilt. A real barrel of laughs. Well, here's the other side of that story. These and a few other episodes stand out in my mind vividly, in part because they were the exceptions, not the rule. While some people find this hard to believe when I tell them, most of my childhood was . . . well, it was *great*. Piedmont Park was a *Wonder Years* type of neighborhood: handsome ranch houses with trees, driveways, patios, and backyards. There, amid the solid suburban middle-class of it all, I did the things most kids of that era did: had fun with my friends, fooled around, played ball, enjoyed video games, watched TV. And although I knew I had this . . . *thing* . . . that the other kids didn't, and I knew I had to take shots every day when they'd get one every couple of years, I wasn't moping around saying "woe is me." In fact, I barely even thought about it.

You see, there's another perspective to type 1. It's not the woe-is-me, this-sucks, I've-been-handed-a-raw-deal perspective, as valid and understandable as that may be. No, in the years since, I've found that I was not the only one who managed to steer a somewhat different course; to put the disease in its place, accept what I had to do, and then get on with the business at hand—the business of being a kid. Lots of other young people with type 1 do this, I've learned. Taking this view usually requires a little help and support from others—in my case, the number-one supporter was and still is my mom.

In my case, I know who it is that enabled me to take a bad break and turn it into an asset I could build on: my mom, Joanna.

While it was still the “Morning in America” Reagan years when I was a young boy, my mom was already practicing something that would become a household phrase during the Clinton administration a decade later: that “it takes a village” to raise a child. Joanna had been deeply affected by some of the other mothers of diabetic children she’d met while visiting clinics with me. “These single moms were crying all the time because they had to do it all by themselves,” she recalls. “I said, ‘I’m not going to let that happen to me.’” She realized that she had to mobilize people around us; she also knew that she would have to take the lead and play the role of recruiter and educator, so that the people responding to her calls knew just what they were expected to do and how to do it.

My mom began doing something a lot of people in her situation are afraid to do: she asked for help. “You’d be amazed how folks will respond when you just ask,” she says. “A lot of good people will step up.”

A lot of them did. Now, maybe this was good old-fashioned southern neighborliness, or maybe they just felt bad for a young mom saddled with a diabetic son and a husband who had disappeared. But I suspect the same would have been true in neighborhoods all over America. Still, we were particularly fortunate that there were a lot of good-hearted individuals living in Piedmont Park in the mid- and late 1980s, some with kids themselves, others not; some professionals, others blue-collar; some native southerners, others transplants—all of them were ready to help.

The one who still comes to mind first, for both my mom and me, is Sheila Costigan, whom my mom met at the local gym. Joanna—with her limitless energy and type A personality—taught

step aerobics at the local health club. Sheila, who had lived in Tallahassee since 1975, took classes with her and became a close friend. Her son Ryan was about my age and was a playmate for me. Sheila remembers the first time Joanna gathered all the moms together for one of her informal “Diabetes Management 101” seminars. “She conducted training sessions, over wine and cheese at my house,” said Sheila. “Joanna would talk about glucose, and glucose shock and how to read the symptoms. She’d talk about what Phil could eat and what he couldn’t.”

I spent a lot of time at the Costigans’, who lived just a couple of blocks away. By the time I was five or six, I had learned what I needed and how to test my blood sugar. So I would tell her that I needed a glass of orange juice because my blood sugar level was low. Sheila became sensitive to my needs. I probably didn’t notice it at the time, but when she made a batch of chocolate chip cookies, she’d let me take one or two, tell her kids to do the same—and then put the rest away, so I wouldn’t feel singled out. When there was cake for somebody’s birthday, it was always sugar-free cake—again, done with me in mind. That was a consideration for which I will always be grateful.

Halloween was a perfect example of how my mom and Sheila would collaborate to help make my life seem a little more like every other kid’s. With all its candies and sweets, October 31 can be a real minefield for a diabetic kid. You can go trick-or-treating but you can’t enjoy the treats, and you feel like an outcast. In order to avoid having me feel that way, Joanna came up with an interesting plan. The neighborhood kids would meet at Sheila’s house. Sheila, Joanna, and a couple of other moms would take us all around the neighborhood, as is typically the case in every suburb in America on Halloween. I would go up, dressed as a Ninja Turtle or a ghost or a football player, go door to door, and get my candy along with

Ryan Costigan and all the other kids. But when we'd get back to the Costigans' house and see how much we'd collected—the culmination of every kid's trick-or-treating—Joanna announced that she had a better offer. She'd *buy* the candy from me: twenty-five cents for a piece of chocolate, ten cents for anything else.

*Hey*, I thought the first time she did this, *not a bad deal*. I knew I couldn't eat that stuff anyway, so why not make some money out of it? I sold my candy to my mom. My friends were watching all this, and the next year they asked Joanna if she'd do the same for them. "Will you buy my candy, too, Mrs. Southerland?" My mom had been hoping they would. Although it probably cost her a little more money than she could afford in those days, these candy transactions were a success on several levels. It kept the sweets away from me, and it kept much of it away from them, as well. After all, while none of them was diabetic, their parents didn't want them consuming all that candy. It ended up making our Halloween a lot of fun, and different from most others. It also became almost like a ritual. The purchase of the candy was made as a group, as if we were the trade ministers of some burgeoning Third World economy dealing with the World Bank. At the end of our trick-or-treating, we'd sit around my or Sheila's house and pool all the candy that we were going to sell. We'd carefully count up how much it was worth and deliver the huge stash to my mom, who would make a big show about checking how much was there. There'd be some haggling, and then finally, after acting as if we kids had driven this really hard bargain, she would sigh and hand over to us what seemed to our eyes a sizable wad of dollars. My friends would squeal with delight over the money, and rightfully so. I remember making between twenty-five and forty dollars, which back in the 1980s was a big stash of cash for an eight-year-old!

My mom jokes today that she may have inadvertently turned a

whole neighborhood of innocent eighties-era kids into the money-hungry hedge fudge managers who helped bring the system down in 2008 through their greed. But it was a good lesson for youngsters embarking on life in a capitalist society, and it certainly helped me feel less singled out because of my disease. It may also have helped to spark my entrepreneurial drive, and the other children learned a lot as well. “Phil taught our kids discipline,” Sheila says. “Joanna gave us adults way more than we gave to her.”

While that’s not necessarily true—my mom and I owe a great deal to Sheila and our neighbors—the discipline Sheila refers to is a steely-eyed seriousness that I began to develop at a young age. While I had plenty of fun being a kid, having the responsibility of being both a diabetic and the “man of the house” forced me to grow up fast. An example of this was food shopping. From early on, Joanna allowed me to watch only PBS. I don’t mean *Masterpiece Theater*, but the cartoons and kids’ shows like *Arthur* and *Sesame Street*. The reason is that PBS at that time had no advertising at all, and Joanna wanted to protect me from the temptations dangled by the manufacturers of sugared cereals, sweets, and soft drinks. When my brother, Jack, and remote controls came along, that began to change. Soon we were flipping around the rapidly expanding cable dial. Yet, my mom says that when she took us shopping, “Jack wanted everything, Phil wanted nothing.” Was it my early exposure to advertising-free TV? Maybe. More likely, I had just made the determination that I couldn’t eat that stuff, and so I didn’t.

If you talk to the people who knew me as a child, they’ll tell you that I was “mature beyond my years.” I’m not always sure if this is a good thing or a bad thing, but it was undoubtedly a necessary thing. Yes, I was a kid and had fun as a kid, but because of the realities of my life—the diabetes and the divorce—I suppose I took on a lot of responsibility early.

Michael Scholl, a friend of my mom's whom she dated for a while, was around the house quite a bit in the late 1980s. He remembers me as this somewhat aloof and quiet kid, with this high-energy mom spinning around me like a dervish, monitoring my blood sugar, making arrangements with the school nurse or the next-door neighbor to help out in this way or that.

My approach was different. I guess I *was* determined: determined to prove anyone wrong who thought I was not capable of doing what any other kid could do, and maybe doing it better. Determined not to let the diabetes rule my life (unless it could help me get things I wanted, like sympathy, favors, and money for my Halloween candy!). Determined to excel, to succeed (although at what, I wasn't sure). Determined to get on with life and to do what had to be done. Above all, though, determined to be a kid—albeit perhaps a slightly more mature one.

I attended Maclay School, a tony K–12 private school about five miles from our house. Located on a one-hundred-acre campus surrounded by a nature preserve, Maclay was founded by a group of parents in 1968. In its mission statement the school declares itself “dedicated to providing a liberal arts education, enabling each student to develop inherent ability to the fullest extent with a balance of discipline and freedom.”

My mom liked the sound of this; I think she also liked the fact that the principal of Maclay at the time, Mr. Jablon, lived three doors down from us. His daughter was in my grade, so I got to carpool to school with the principal. The Jablons were part of the solid neighborhood fabric; when my mom got divorced and was struggling financially, they allowed her to continue sending me to the school at considerably less than the regular tuition.

By the time I set foot at Maclay, my mother had thoroughly briefed Mr. Jablon, the school nurse, and all the teachers—probably

even the custodian and groundskeepers—about my condition. I'm glad she took the precautions, but fortunately, their readiness was never tested. I recall only one diabetes-related “crisis” at Maclay, if you can call it that. It happened in kindergarten. One morning, my blood sugar was low and I needed to eat in order to bring it back up. So, apparently, I found the lunchbox of my one of my classmates and, while no one was looking, opened it up and ate her lunch. When she discovered her lunchbox empty, the teacher called the class together. “Who ate Amanda’s peanut-butter-and-jelly sandwich?” I admitted that I had done it, and explained as best as a kindergartner could that my blood sugar was low. Both my lunchless classmate and my teacher were understanding, which I remember thinking was nice of them.

That’s pretty much it. I stayed at Maclay through seventh grade, and what stands out from my years there are . . . well, the same kind of memories you might have. Teachers I liked. Playing football on the playground. My friends. Christmas pageants. Field trips. Nothing really out of the ordinary. But you know what? It’s nice to have ordinary memories. It shows that I wasn’t standing out in school because of my diabetes. I was just another kid.

At home it was maybe a bit of a different story. I took that idea of being the man of the house seriously. Mom remembers we had this cat named Moon that she particularly loved. But one day a neighborhood dog got loose and caught our cat and killed him. Joanna was mortified; she wept like a baby. I realized that she was in no condition to take care of what had to be done. So, I gathered up Moon’s mangled body, buried him in our backyard, and tried to console my mom the best I could. It was hard, and I knew how terrible she felt, but somebody had to be there to do what had to be done.

That someone would be me—then and for the rest of my childhood and adolescence. I guess when you inject yourself four times

a day, and regard a trip to the emergency room as a sort of semian-  
nual field trip, other things in life, whether pleasant or not, are put  
into perspective pretty quickly. Because you had to become sensi-  
tive to changes that could happen very quickly in your body—and  
with life-or-death consequences—you also learned how to size up  
a bad situation quickly.

There was the time a guy, supposedly a friend of my mom's,  
came by and put his arm around me in a way that even to me at  
age nine seemed a little too intimate. I broke free and hid in a  
neighbor's garage until he left. I don't know what ever happened to  
him, but I'm sure that Joanna, with her good radar for judging  
people, made certain he didn't come around anymore.

About a year later, Joanna went out to the West Coast with a  
guy she was dating. While she was away, she had arranged for my  
brother and me to stay with my aunt—Mom's sister, Tricia—who  
was living in St. Petersburg. But when I got there, I sensed that  
things weren't right. Tricia had her own challenges at the time—  
she was a single mom trying to raise four kids. The house was  
kind of a mess. There was no food in the refrigerator. My aunt was  
going through a difficult period in her life. She was overwhelmed,  
and I certainly don't blame her for that, but it became apparent  
pretty quickly to me that this was not a place where we should be.  
She was simply not able to take care of two more kids, even for just  
a few days—which my mom hadn't known when she sent us down  
there. I knew it was best for us to leave. I didn't call Joanna in Or-  
egon, because I realized then there was nothing she could do from  
there that I couldn't do myself. So I got on my aunt's phone and  
called Sheila Costigan. Told her the situation, asked if we could stay  
with her until my mom came back; she said sure. I arranged for  
a cousin to drive us back to Tallahassee, to the Costigans' house,  
where we stayed until my mom got home. Although we'd handled

the situation, and Jack and I were not the least bit traumatized from spending a day or so in my aunt's messy house, I'm sure I played up the guilt with my mom: "How could you leave us and go out to Oregon with that guy?" In hindsight, I acted like a real jerk with all the guys my mom tried to date. I don't know why I did this, because I needed a father figure. Man oh man did I need one. He would arrive, although in an unexpected way.

different, I just have to make adjustments. I also want you to know that whatever technology you currently are using to control my blood sugar is going to change, and will change drastically. At first it will be overwhelming, but it will get better and better. The technology is going to point out our errors. I am going to have high blood sugars and will go to the hospital because of them, and I am going to have low blood sugars, which will also take me to the hospital. But I will live!

Mom, you are going to watch me have seizures, and please know that even though I will come to the brink of death on more than a few occasions, it's not my time yet, and more importantly, it's not your fault. I am a fighter, Mom, and that is how you have raised me. You will do things for me that will help to revolutionize the world of diabetes, and I promise that one day you will be able to sleep through the night. I would like to ask you to do one thing for the family, and that is for any amount of attention you give to me as a diabetic kid, please give equal or more attention to my brother (yes, you will have another) as he grows up. The odd thing is that in a family of a kid with diabetes, the sibling without diabetes is often "the othered."

I am going to fight with you, and I am going to argue. I will even refuse to eat broccoli. But I ask that you sit there with me for two hours until I finally cave and eat it. Your stubbornness will define my being for the better, and I will try to take all the good that you are, and the heart and soul you put into me, and pass it on to the children of the world. Please let me know the side effects that poor control and discipline can bring. Please don't let me take for granted the fact that I have insulin and test strips. I feel extremely lucky for the people that you will bring into our lives, and for the lessons you will enable me to learn.

In hindsight, I would also like to thank you for standing strong

when I argued about college. Your decision for me to go was brilliant, as was your “business plan” call several years later. As time will tell, you have been right about a lot. You have done this because if you believe it to be a lie, then it is a lie, or if you believe it to be true, then it is true.

This is the very same belief system and passion that you have instilled upon me. It is because of everything that you have done that I now see it as wrong that children do not have access to the supplies I once tried to refuse taking. It is because of this that I will not quit working until they have them in their hands, and they know how to use them.

I know I may sometimes seem distant and unavailable, and for that I am sorry. I am sorry I don't call or write like a “normal son” does, or that I only come home once per year now. You have instilled in me “The Power to Change” and with that power comes responsibility. Just as you once gave up everything to ensure I stayed alive, I too now give up some things to ensure these other kids live. I have a dream now, Mom, a dream that I wake up in a world where nobody goes blind from diabetes. It is your commitment toward ensuring that I can still see (which I can) that will one day ensure we all see.

Mom, Dad, Jack (yes, you will name my brother Jack): I love you all. You are my family and have been there when I truly needed you, and am forever grateful for your love and support. You are in a dire time right now, but again I would like you to know that I have many years left in me, and I hope you raise me just the same in this second round. It's still not my time!

Love and thanks,  
Philpott