Stopping Diabetes Through Advocacy: The Role of Health Care Professionals

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Geralyn Spollett, President of Health Care and Education for the American Diabetes Association (ADA), is a busy nurse practitioner at a large New England medical school. Why did she cancel her patient hours to meet with training officers of a metropolitan police department?

George Grunberger has a busy one-person diabetes private practice. As with most practicing physicians, his income depends on seeing patients. So what was he doing in a Washington, D.C., conference room discussing truck driver licenses on a busy weekday?

"First of all, it gets me out of my office. I learn about new things, and the work is interesting and exciting," Grunberger said. "Second, although much of it is *pro bono*, not all is. Consulting fees certainly make up much of the lost income from time away from the practice and broaden my business relationships. Third, my job as a physician and diabetologist is to help people with diabetes live their lives better. This is part of the job. If my patients are not able to work in their chosen professions, it directly affects their quality of life and, potentially, health insurance and ability to afford their diabetes supplies."

But, health care professionals (HCPs) do not have to give up office hours or travel to the nation's capital to be an effective advocate for their patients. There is a great deal we can do in our own hometowns. In the remainder of this article, the authors offer insights from their own experiences as advocates.

Dan's Experiences: Employment Discrimination

Sam is a firefighter with type 1 diabetes in New York City, where I work. He was placed on desk duty and filed a suit against the Fire Department of New York City (FDNY) for discrimination under the Americans with Disabilities Act. He was referred to me for an independent medical examination. My report and subsequent deposition were used in negotiating a settlement that enabled Sam to take a leadership position on a New York City fireboat in July 2001. Two months later, he spent 3 days pumping water from the river into Ground Zero.

OK, so you don't want to deal with the legal system. You don't have to.

Another patient, John, is a 24-year-old man who has had type 1 diabetes since the age of 18. He is currently using an insulin pump and wants to become a New York City police officer. When he was concerned about possible restrictions for people with type 1 diabetes, I referred him to the ADA Legal Advocacy staff. We worked together to help him decide on the best route to becoming a police officer.

Another patient, Bob, wanted to become a member of FDNY. After reviewing the National Fire Protection Agency's guidelines for employment of people with type 1 diabetes, it was obvious that Bob clearly met the criteria, and a detailed physician letter to FDNY resulted in his being hired.

Harry has type 2 diabetes with elevated A1C despite use of maximal oral antidiabetes agents. When I suggested treating his diabetes with insulin, he refused because he was afraid he would lose his job as a New York City bus driver if he was on insulin. After reviewing the regulations with him, including the steps he would need to take to fight for the job, Harry chose to take another job with the bus company that did not require a commercial driver's license so he could avoid a legal battle and focus on achieving better control of his diabetes.

What's in it for you, a busy diabetes professional?

Working with the Department of Transportation (DOT) gave me the opportunity to educate other physicians and DOT about diabetes and to work toward modification of commercial and private driving licensure requirements. Further, it gave me an additional area of knowledge and expertise that led to consulting opportunities.

Learning about the concerns of Fire Department or Police Department physicians enabled me to better counsel my patients on their career paths and support them when they chose to proceed with a safety-sensitive job. In some cases, it also gave me the background to

counsel them against a public safety or fire-fighting position.

Helping Sam enabled me to make a small contribution to New York's response to the terrorist attacks of September 11, 2001.

Legislative and legal advocacy efforts are woven throughout the ADA Stop Diabetes movement and the Association's 2012–2015 strategic plan. This plan lays the groundwork to change the diabetes landscape and stop a disease that is devastating our patients, communities, health care systems, and economy. HCPs play an important role in these efforts.

Your professional expertise, combined with your patient encounters, is all you need to be an effective advocate. From the start of the health reform debate, medical professionals have worked to increase awareness of diabetes and address ways in which our health care system can be improved to help people with or at risk for diabetes.

Gina's Experiences: Inadequate Insurance

In March 2009, at a press conference on Capitol Hill to discuss how health reform would benefit people with chronic disease, I shared my experience of living with type 1 diabetes, highlighting that my health is largely a result of having access to affordable and adequate health insurance. I compared my experiences to those of one of my patients.

Joe, a 30-year-old uninsured college graduate with type 1 diabetes, came to the Emergency Department of my hospital with a needle embedded in his thigh; the surrounding area was grossly infected. Money was tight for his family. To save money, he re-used his syringes until he couldn't push them through his skin anymore. A needle had broken off in his leg, and Joe hoped it would work its way out like a splinter, but it hadn't. He was admitted to the hospital awaiting a surgical consult. This didn't need to happen, but it did as a result of Joe not being able to afford essential diabetes care.

The health insurance climate causes us to advocate daily to "pre-authorize" or "pre-approve" procedures, medications, and diabetes supplies. To complicate matters, many of our insured patients do not have coverage of basic diabetes survival needs. For others who are uninsured or have reached their annual or lifetime caps on insurance coverage, and for those who have been denied health insurance, had their coverage dropped, or pay higher premiums because of pre-existing conditions, the situation becomes even more overwhelming.

David, a 34-year-old security officer, has private health insurance that does not cover brand-name medications. Each month, he uses two boxes of both lispro and glargine insulin pens costing > $1,000. Karen, a 30-year-old woman diagnosed with gestational diabetes, has health insurance, but it does not cover diabetes education. Neither David nor Karen can afford these expenses. And both, as well as Karen's unborn baby, run the risk of costly complications.

Gloria is 64 years old and 1 year away from Medicare eligibility. Her type 2 diabetes and other chronic medical conditions have exceeded her health insurance policy's lifetime cap limits. Struggling to pay for her medical expenses, Gloria and her husband have drained their savings and are thousands of dollars in credit card debt.

Advocacy efforts are helping to eliminate these barriers. As Congress began discussing health reform, hundreds of patients, doctors, nurses, dietitians, diabetes educators, and other HCPs addressed the need for these essential components of diabetes management, and advocacy efforts carry on as provisions continue to be determined. Personal stories such as those of David, Karen, and Gloria were shared and left lasting impressions.

Medicaid services for millions of Americans with diabetes help to decrease the high costs of preventable emergency visits and hospitalizations. As the government works to balance the budget, all such programs run the risk of deep cuts. In September 2011 at a news conference in Washington, D.C., to discuss how potential cuts to Medicaid would endanger Americans who rely on this safety net for their diabetes needs, I shared the following story:

Margaret, a 51-year-old woman with type 1 diabetes, lost her Medicaid coverage because of a slight increase in her income. Removal of this safety net left her vulnerable. Like so many others, she rationed her insulin and test strips. She postponed seeking medical treatment for a blister on the bottom of her foot until it became infected and required surgical debridement. The post-surgical wound became infected, and, eventually, her leg was amputated. This physical and financial tragedy could have been prevented.

Stories such as this were remembered, retold by the media, and referenced at congressional hearings and made a significant impact on discussions pertaining to health reform and Medicaid.

Advocacy Makes a Difference

Advocacy successes often result from cumulative individual and group efforts. The media are full of articles about the epidemics of diabetes and obesity and the success of lifestyle-change programs in addressing these problems. These programs and research did not just appear; they

took commitment and federal grant support to make them happen.

Positive changes have resulted from HCPs and others e-mailing, calling, and meeting with their members of Congress to address the need for increased federal funding for diabetes research and programs. Federal funds awarded to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) made the landmark Diabetes Prevention Program clinical trials possible. This research concluded that people can reduce their risk for developing type 2 diabetes by 58% (and up to 71% for seniors) through lifestyle change and modest weight loss. Federal funding at the Division of Diabetes Translation (DDT) at the Centers for Disease Control and Prevention made it possible for this research to be used to create cost-effective community diabetes prevention programs.

When the Patient Protection and Affordable Care Act became law in March 2010, the National Diabetes Prevention Program (National DPP) was included in this health reform legislation; however, no money was allocated to support the program. Doctors, nurses, dietitians, and diabetes educators continued speaking with their members of Congress to address the need for funding for this program, which would result in significant improvements in health outcomes and cost savings.

In March 2011, at the ADA Call to Congress, a lobbying event on Capitol Hill bringing together diabetes advocates from across the country, HCPs joined adults and children living with diabetes and met with their members of Congress to explain the connection between NIDDK's research, DDT's programs (emphasizing accomplishments that resulted from congressional funding for these projects), and the National DPP. This set the stage for advocates to spotlight the need for funding for the National DPP. Thanks to these advocacy efforts, the National DPP recently received $10 million in federal funding, which will provide funds to build national infrastructure for the National DPP and to award grants to community organizations for programs that will help prevent type 2 diabetes.

A Call to Action

We cannot expect such changes to occur if we do not bring into the spotlight the issues that affect our patients and our ability to provide patient care. ADA advocates for all people living with or at risk for diabetes, working in the following four areas:

- Fighting discrimination
- Preventing diabetes
- Improving access to health care
- Increasing funding for diabetes research and programs

Advocacy, like politics, is often local. It takes place in our offices, on our patients' worksites, through local and state governments, and on a national level as well. There is a common misconception that becoming an advocate means you will have to be an expert witness and testify at the mercy of opposing attorneys or that you will need to speak before members of Congress regarding pending legislation. Although serving as an expert witness and speaking at events on Capitol Hill are two advocacy opportunities, they are by no means the only, or the most common, ones. Table 1 offers some ideas for how to become involved as a diabetes advocate.

A good way to start your journey as a diabetes advocate is by identifying your connection to diabetes. What do you do every day? With whom do you interact and in what capacity? Are you interested in research, diabetes management, prevention, or some combination of these? Let these connections guide your efforts.

HCPs in all fields can advocate by asking patients if they have any problems being allowed to perform diabetes care tasks at school or work and by referring those who do to the ADA 1-800-DIABETES phone number. Familiarize yourself with advocacy issues affecting your patients and profession and speak out about what is needed for your patients with or at risk for diabetes. Make ADA's advocacy materials

Table 1. Advocating for Your Patients and Others Who Have Diabetes

- Contact the ADA at 1-800-DIABETES (1-800-342-2383) to talk to a legal advocate about how to help your patients and others fight unfair treatment.
- Become a diabetes advocate and receive urgent action alerts and information about how you can help end this epidemic through advocacy. Sign up at www.diabetes.org/takeaction.
- Learn more. Eliminating disparities in health care is a major focus of the ADA. For more information on the disparate impact of diabetes in minority communities and the advocacy response to this issue, visit http://www.diabetes.org/advocate/our-priorities/disparities.html.
- Assist with legal issues. ADA has a network of volunteer health care providers who work together with staff to protect the legal rights of adults and children with diabetes at school, in the workplace, at correctional institutions, and in other public places. Learn more, and join the Health Care Professional Legal Advocacy Network by visiting www.diabetes.org/patientrights.

available in patient areas. Be ready to help your patients avoid or stop discrimination by filling out forms that set the stage for how they are treated at school or work or even in jail and by educating decision-makers about what is needed to successfully manage diabetes. Much of the discrimination people with diabetes face is based on a lack of awareness about the disease in the general public; you are in a position of power to help raise awareness.

Visit www.diabetes.org/patientrights for a variety of resources for HCPs whose patients are facing discrimination, including sample letters you can use to help your patients secure needed accommodations at work and training materials to help children receive appropriate diabetes care at school.

The legislative process provides a range of opportunities, from sending e-mails to speaking on Capitol Hill, for HCPs to be involved. Remember, you do not need to be an expert on politics; what is needed is your expertise on diabetes. We need to share that expertise with those in a position to effect change: our elected officials at the local, state, and national levels.

Legislators repeatedly ask to hear from their constituents. Few, if any, state or federal politicians have a health care background, and the same is true of their staff members. Your voice, as a member of the health care community, is powerful, and your interactions leave an impression. Understanding diabetes and the struggles your patients face when health insurance is not accessible, affordable, or adequate provides the opportunity to educate decision-makers about dangerous and costly health outcomes that can often be prevented and about the need for further research to stop the diabetes epidemic.

The moments of greatest impact have been those in which the human side of diabetes was told. Personal stories—successes and tragedies—are the stories legislators want and need to hear. These are the stories that are remembered.

Awareness of the ADA's advocacy efforts and resources has allowed us to be a part of legislative and legal successes that affect the patients we care for and our professions. Lobbying Congress with friends from the ADA has also provided us with a great education in how our legislative branch of government works. We invite you to join us in our efforts to Stop Diabetes through advocacy.

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