Testimony of Robert S. Amato

From Johnston, Rhode Island

At the Hearing entitled:

"Diabetes Research: Improving Lives on the Path to a Cure"

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Chairman Collins, Ranking Member McCaskill and Members of the Committee, thank you for the opportunity to testify before you today. My name is Bob Amato and I am from Johnston, Rhode Island.

When I was first diagnosed with type 1 diabetes sixty-seven years ago at the age of seven, the thinking was that people like me should not participate in sports or lead an active life. This seemed unreasonable to me and with the guidance of the many physicians at the Joslin Diabetes Center, along with my family, I was able to prove this concept to be a fallacy. In 2009, I was entered into the Athletic Hall of Fame at Providence College because of my accomplishments as a runner and coach. As a coach, I had the privilege of guiding a runner to two consecutive World Championships, the team to 16 New England championships, and 23 athletes were selected as Division 1 All Americans. My coaching colleagues selected me as "University Division 1 Coach of the Year" 15 times.

I was able to find success despite the daily challenges of diabetes because I always used the latest technology to help me better control my diabetes and keep myself healthy. However, at the present time, I am hindered from continuing my successful and active lifestyle. About 15 years ago, I began to realize that the normal warning signs for hypoglycemia – or low blood sugar – were diminishing. Previously, as my blood sugar neared a dangerous low level, I would experience dizziness, sweating and shakiness, which would give me the time to eat or drink something to prevent me from passing out, having a seizure or worse. With hypoglycemia unawareness, I started experiencing many close calls and my quality of life was beginning to suffer. I needed a better way to manage my diabetes.

I was fortunate to participate in a JDRF-funded research study using a continuous glucose monitor, or CGM, which measures blood sugar in real time and alarms when blood sugar levels are about to go too high or low. The difference was life changing. The CGM provided not only an essential early signaling of a low blood sugar but essential data to help me better control my diabetes overall.

As a result of the JDRF study and other studies, the use of CGMs has been endorsed by the leading clinical societies involved in treating people with diabetes – the Endocrine Society, the American Diabetes Association and the American Association of Clinical Endocrinologists. Even private insurers recognize the importance of this technology. In fact today, over 95 percent of private plans cover CGMs for people with type 1 diabetes.

But here's the tragedy – Medicare does not cover this life-saving device so I had to stop using the CGM after the study and my serious hypoglycemic events returned. For the past 4 years, I have been appealing the decisions of Medicare in an effort to get coverage. In 2014, an Administrative Law Judge ruled in my favor, but the Medicare Appeals Council rejected the ruling, and I am yet again left without coverage for this device.

Now that I depend on Medicare for my diabetes care, the CGM that has saved my life countless times has been taken from me. I cannot and will not accept CMS' decision, for me or for all the seniors with type 1 diabetes who depend on this device.

The CGM can mean - literally - the difference between life and death. I was once on an interstate when my blood sugar plunged without me noticing, and I began driving erratically.

Fortunately, an 18-wheeler intentionally crashed into the side of my car to push me off the highway. No one was injured, and that truck driver possibly saved my life and that of others. A CGM would have alerted me well before this precipitous drop in blood sugar and the accident would have been avoided.

I had a chance to visit Providence College recently, and I stopped in at the Hall of Fame to see the plaque I received several years ago. I remembered the excitement of recruiting athletes in Ireland, England, Scotland, and all parts of the United States. I remembered the World Championship in Ireland when runners from the Providence College team were represented on the Irish national team, the English national team and the American national team. I also remembered this as a time in my life when I was able to travel the world because managing my diabetes wasn’t so incredibly difficult.

I loved coaching. It gave me so much – including a livelihood that allowed me to pay my share in to Medicare. It is so disappointing and unnecessary, that at this stage of my life, I am almost incapable of doing very much at all. The CGM would allow me to be active again, yet without it, I can only go a short distance from my home unless my wife or a friend is with me. This is not how I want to spend the rest of my life. It’s an injustice that needs to be rectified.

Chairman Collins, thank you for recognizing the importance of this issue and for introducing S. 804, the Medicare CGM Access Act of 2015, which would ensure that Medicare covers CGMs for seniors like me. I would also like to thank the others on the panel who have signed on as cosponsors and urge those of you who have yet to cosponsor to support this effort. Congress is doing an outstanding job of providing funds to advance type 1 diabetes research; however, the benefits of these advances will be limited unless there is coverage.

Thank you for the opportunity to testify. I am happy to answer any questions you may have.