

CREATING CHANGE CAN BE FUN

Ensuring that amputees across the United States have access to appropriate prosthetic devices is the number one goal of the Amputee Coalition of America. Two years ago in Colorado, a group of amputees and prosthetists were able to successfully enact legislation mandating that insurance companies pay for prosthetics. This article will share with you their format for success and the encouragement that you can make the same difference in your state.

by Jeffrey J. Cain, MD

Two years ago, sitting in his prosthetist's waiting room, Mike Johnson was depressed. An above-knee amputee for 10 years, he normally could be found enthusiastically teaching his high school shop class or leading the local amputee support group. But this day, Johnson had just found out that his insurance company no longer covered his prosthesis.

With your interest and help, it doesn't have to be this way.

The last 10 years have brought a change in the way that insurance companies cover (or, more accurately, do not cover) prosthetics. Increasingly, coverage is limited to inadequate Durable Medical Equipment (DME) limits of as little as \$1,000, lifetime limits, or caps on total payments, leaving amputees unable to afford prosthetic devices.

Changing insurance laws in your state to include prosthetics involves six steps:

- Forming a group
- Understanding the legislative process
- Fundraising
- Building a grassroots organization
- Introducing legislation
- Having fun.

Having fun?

How can you have fun running a legislative project? In Colorado, our group started with members of local amputee support groups and prosthetists, and over the year that we worked together, we discovered our members also had political, leadership and other hidden skills. Our monthly meetings often started with pizza and ended with adult beverages and laughter.

Your legislative group would do well

by starting with people you know would support the goal of insurance coverage for amputees. You can find them at amputee support groups, parent support groups, and among the prosthetists that you work with already. To help you in the process, the ACA has published a guide titled *Prosthetic Parity Law State Organizers' Toolkit*, which is available through our national office.

Understanding how a bill becomes law begins with finding out which members of your group stayed awake during their fifth-grade civics classes. Though each state varies, the legislative process in most states mirrors the national legislative process. Bills are introduced into a legislative body (the House or Senate), work their way through appropriate committees, and are voted on by the whole. The same process is repeated in the other body, after which the governor

may sign the bill into law.

It will be important to find a sponsor for your bill who can guide it through this process and influence legislators. Lobbyists can be helpful because of their knowledge of the process and their access to legislators.

In Colorado, we chose to model our bill on Medicare, which covers the most appropriate prosthetic device defined by the amputee's ability and his or her doctor and guarantees payment of 80 percent of the cost of the prosthesis.

Nobody likes asking people for money, but fundraising is a necessary part of running legislation. In Colorado, we found that amputees and prosthetists were willing to share in the costs of running a campaign, either through the donation of money or time.

A grassroots organization allows you to ask individual amputees throughout your state to contact their legislators with your message. It is widely known that legislators will pay attention if they hear from just two or three of their constituents. We put our grassroots group together with a combination of mailings from the ACA, prosthetists' offices and an online action group.

We learned to not underestimate the broad support of legislators for the premise that artificial arms and legs are important for basic healthcare. Our message was clear: Prosthetic limbs enable amputees to return to work, family, and life. This theme was supported by legislative members from both sides of the political aisle and was reflected in the name that we chose for our group, the Colorado Coalition of Working Amputees (CCWA).

So why should you participate in an effort to ensure adequate insurance coverage for amputees?

In addition to the selfish reason of individually wanting to be able to afford a leg to stand on, our members learned that we could make a difference not just for ourselves but for others as well.

Today, two years after our year of teamwork, Mike Johnson is back on his feet in front of his class with new confidence in his new leg and in the knowledge that he has contributed to the future of amputees that he will never meet.

Oh, and did I mention that we had fun too? ■



About the Author

Dr. Jeffrey Cain, a double below-knee amputee in Denver, Colorado, is one of the founders of the CCWA and a member of both the ACA Board of Directors and the ACA Medical Advisory Committee.