Taking the Lead in Campaign for Change

The time for talk has passed. The time for action is now!
The Amputee Coalition of America (ACA) is taking the lead in a campaign to change inadequate laws regarding prosthetic reimbursement. In a recent membership poll, access to adequate prosthetic coverage was the No. 1 priority for individuals living with the loss or absence of a limb. As the ACA goes forward, it’s important that it head this effort in cooperation with other prosthetic and health-related organizations and companies. The time for talk has passed. The time for action is NOW!

Medical costs are increasing dramatically while reimbursement funds are decreasing. Suddenly, we are finding that our prostheses are no longer covered by insurance or that our coverage provides inadequate Durable Medical Equipment (DME) lifetime limits, or caps on total payments, leaving us unable to afford prosthetic devices that help us live our lives fully.

The ACA leadership recognizes that a public health crisis for individuals living with limb loss or limb absence is imminent as they become increasingly at risk of living a sedentary lifestyle due to an inability to access appropriate prosthetic care. Therefore, an aggressive course of action has been approved to ensure that such care is afforded to all consumers, and Phase 1 of the “Campaign to Improve Access to Prosthetic Care” will be launched in March 2004, marking a new and significant milestone in the history of the ACA.

The ACA Board of Directors, ACA staff and legal counsel have developed a plan to lead the campaign to mandate coverage of prosthetic limbs at or greater than the Medicare level, and we are now ready to initiate Phase 1. It is important to note at the outset that the ACA cannot accomplish this alone. We must have the support of O&P professionals, the industry, and other health-related organizations. We need amputees and their family members to come forward and participate because legislators respond to calls and letters about issues of concern to voters in their area.

While we are working towards federal changes, we will also continue to work with groups who are, or will be, working to enact legislation mandating that insurance companies pay for prostheses within their own states. In the last four years, Colorado, Maine and New Hampshire have passed prosthetic parity laws. Massachusetts, Connecticut and New York are in the process of pushing bills through their legislatures, and Washington State is working on introducing a bill in 2005.

Jeffrey Cain, MD, an ACA Board member and chair of the Public Policy and Advocacy Committee (PPAC), was the driving force behind Colorado’s bill in 2000. “Amputation is an equal opportunity disability and crosses political lines,” Dr. Cain says. “People on both sides of the political aisle support this effort. It’s a very compelling issue for the public. Most people think that if they were to suffer a limb loss, their insurance company would pay for an appropriate prosthetic. However, when we polled 100 privately insured people in Colorado, we found that only 20 had policies that adequately covered prosthetics. Eighty percent of those polled found that if they lost a limb that they could not afford an artificial limb.”

“The push in Colorado was about helping amputees return most effectively to their lives,” Dr. Cain continues. “We found that by working together with the amputees and prosthetists in our state we were able to put together an enthusiastic coalition of people who had little experience but a lot of passion.”

Dr. Cain’s article in the May/June 2003 issue of inMotion, “Creating Change Can Be Fun,” outlines the steps involved in changing the law in a state:

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

Keith Cornell, president of AOPA, feels that a multi-state and federal approach can be successful and that the more states with prosthetic parity laws in place by the time it comes to vote on federal legislation, the better chance we will have that the legislation will pass.

How is ACA going to set about this necessary but daunting task? Douglas
McCormack, ACA’s general counsel, says that the focus of the campaign’s first phase will be to:

- Develop a comprehensive understanding of the legal, regulatory, statutory, insurance industry and political underpinnings that influence prosthetic access
- Identify and recruit industry and related organization stakeholders to participate in developing a comprehensive response to improving prosthetic access
- Establish the first inclusive, coherent and cohesive strategy encompassing the views and recommendations of the entire O&P community and related stakeholders to be detailed in an access to care and limb loss access blueprint or action plan.

As we indicated previously, this is part of a public health issue. Each year 185,000 Americans undergo amputation of a limb and about 1,000 children are born with a limb difference. Nearly 1.28 million people in this country are living with the loss of a limb. While there has been a marked decrease in the number of injury-related or traumatic amputations, due to innovations in treatment and injury prevention, there has been a sharp increase in the number of new cases of amputations in people with diabetes and peripheral vascular disease. More and more morbidly obese children and young adults are at risk of being diagnosed with Type 2 diabetes, putting them at risk for amputation of a limb at a much younger age. Prevention is obviously the best approach, but when that is unsuccessful, ACA intends to actively engage organizations interested in ensuring quality outcomes in people with limb loss to chart a course for establishing national goals to improve their health and quality of life.

“It’s important to ask ourselves where do we want to be in 10 years and then work to create that future,” Dr. Cain adds. “If current insurance trends continue, fewer and fewer of our members will be able to afford prosthetic devices and their quality of life will be limited. If we take a leadership role, we can help to create a future where all amputees in the U.S. have access to the appropriate prosthetic devices that ensure them as productive a life as possible.”

How can you help? Get the word out through your support group, prosthetists and other healthcare providers. If you don’t belong to a support group, call ACA for the one closest to you. Be proactive. Start a legislative group in your state.

ACA has published a guide titled Prosthetic Parity Law State Organizers’ Toolkit, which is available through the national office. The ACA has a database of experienced individuals who are willing to help new groups get started. As those groups gain experience, they will be added to the database to help the next group. In this way we can all contribute to the future of every amputee.

To be a success, this must be a consumer-driven campaign. It will benefit each one of us and generations to come. No one expects to be born without a limb or to have one amputated. The time to find out that a prosthetic device is not covered by your insurance plan is not after a catastrophic event when you are already in tremendous physical and emotional pain. When you are facing drastic lifestyle changes, you certainly do not have the energy or time to challenge your insurance company. That time and energy should be used to recover, rehabilitate, and return to an active, productive lifestyle.

Join ACA and its partner organizations in this effort. We are establishing a new category for receiving donations. Every donation, however small, will help. Just think, if every amputee in the United States sent in just $1 every year, we would have $1.28 million dollars a year to help us make this happen. Be a part of a history-making initiative and send in your donation today. Together we will make this happen.

Send your donations made out to the Amputee Coalition of America to: ACA, 900 E. Hill Avenue, Suite 285, Knoxville, Tennessee 37915-2568. Please include a cover letter stating that your donation is for the “Access to Care Campaign.”

To make a donation by credit card go to the “Your Dollars Make A Difference!” icon on the ACA Web site at www.amputee-coalition.org and click on it. Then click on the “Advocacy Contribution” link.