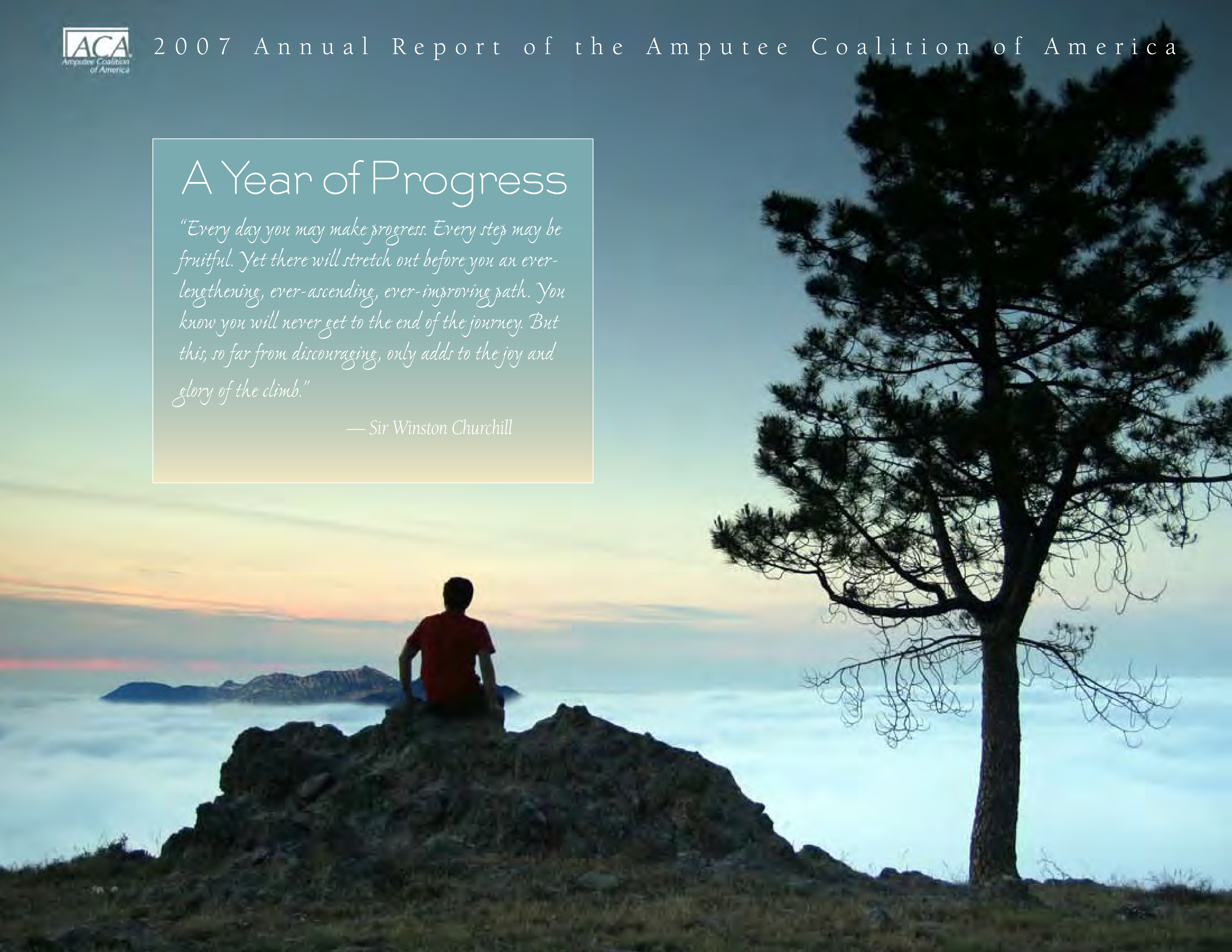
2007 Annual Report of the Amputee Coalition of America

A Year of Progress

"Every day you may make progress. Every step may be fruitful. Yet there will stretch out before you an ever-lengthening, ever-ascending, ever-improving path. You know you will never get to the end of the journey. But this, so far from discouraging, only adds to the joy and glory of the climb."

— Sir Winston Churchill



OUR MISSION

To reach out to people with limb loss and to empower them through education, support and advocacy.

In Support of Our Mission

Advocacy

ACA advocates for the rights of people with limb loss or a limb difference. This includes access to, and delivery of, information, quality care, appropriate devices, reimbursement, and the services required to lead empowered lives.

ACA promotes full implementation of the Americans with Disabilities Act and other legislation that guarantees full participation in society for all people, regardless of disability.

ACA sensitizes professionals, the general public and policymakers to the issues, needs and concerns of amputees.

Support

ACA's National Peer Network certifies people with limb loss to provide support and information for others who are just beginning the road to recovery.

ACA's toll-free hotline provides answers and resources for people who have limb loss or a limb difference and those involved with their lives.

Education

ACA publishes *inMotion, First Step* and other magazines that comprehensively address areas of interest and concern to amputees and those who care for and about them.

ACA develops and distributes educational resources, booklets, videotapes, and fact sheets to enhance the knowledge and coping skills of people affected by amputation or congenital limb differences.

ACA's National Limb Loss Information Center is a comprehensive source of information about amputation and rehabilitation.

ACA provides technical help, resources and training for local amputee educational and support organizations.

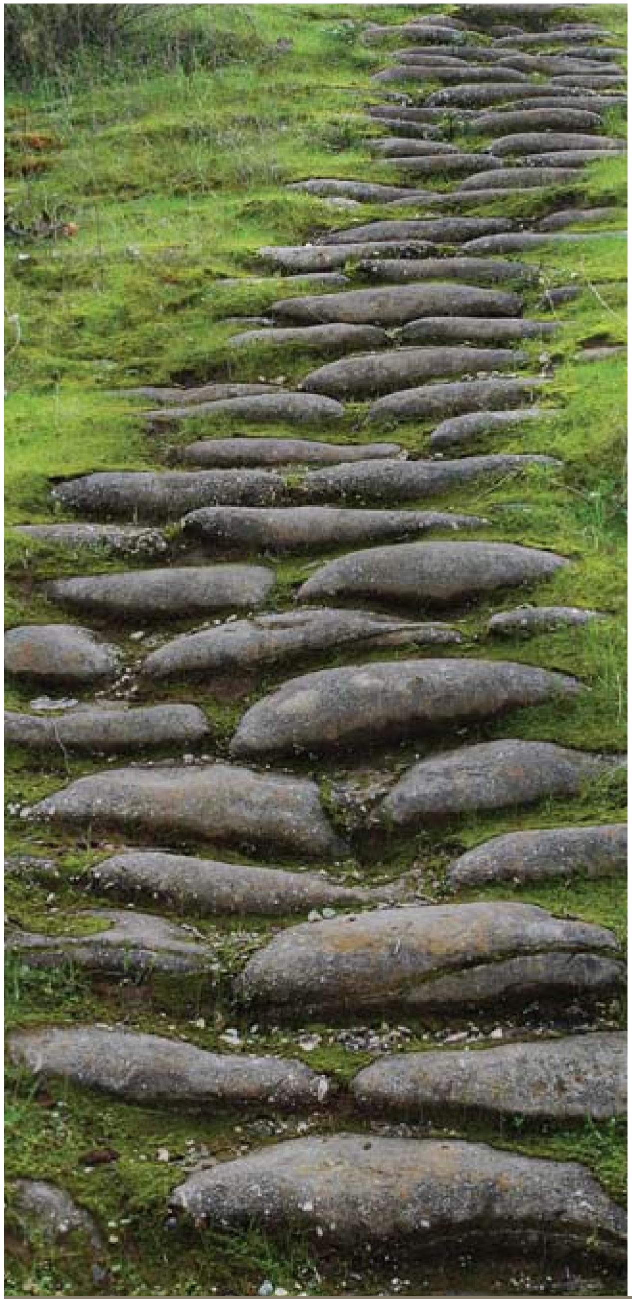
ACA conducts programs for its members, professionals and the general public to educate them about the physical, emotional, technological, and other issues of amputees.

Credits
Written/Compiled by Kendra Calhoun
Edited by ACA Communications Department
Designed by Karen Alley and Patrick Alley

About the Cover

Like this traveler who sits atop a mountain, the Amputee Coalition of America has already attained great heights. However, the ACA has a much larger vision, represented by the mountain in the distance. Though this vision might at times seem impossible to reach, the organization is ready and thrilled to take up the challenge. Forward!

“My own experience and development deepen everyday my conviction that our moral progress may be measured by the degree in which we sympathize with individual suffering and individual joy.”
— George Eliot



MESSAGE FROM THE CHAIR

Progress is the theme of our 2007 Annual Report, because this year has been a year of moving forward.

The ACA's Prosthetic Parity Campaign, which was launched in 2006, has proved to be particularly successful this year and has provided a solid foundation to build on in years to come. This success would not have been possible if not for the many grassroots volunteers around the country who have given countless hours to see parity made a law in their state. For those who are still striving toward parity, we will continue to bring our resources to bear to assist your efforts as you march your state toward fair and equal treatment for prosthetic care.

Progress has come in a variety of forms this year: new volunteer programs, expanded outreach, enhanced online materials and the renewal of the Centers for Disease Control and Prevention (CDC) grant that provides funding for our National Limb Loss Information Center. The CDC's continued confidence in the ACA has been steadfast over the years and continues to ensure the ACA's position as a first-rate resource for the limb loss community.

Progress this year meant that we invested more resources in areas the board of directors identified as mission critical. Our advocacy work was such an initiative. While this activity has not yet begun generating funds to support all of its work, it is providing an invaluable benefit to our

"I walk slowly, but I never walk backward."
— Abraham Lincoln

many members who are relying on private insurance programs. However, you will see that this investment is reflected in our financials at year-end.

The ACA staff and the board of directors strive to provide valuable services with limited means. We have quantified some of those services on pages 37-42. Our strategic thrust is for the ACA to grow diversified revenue streams so support programs can be expanded and other mission-based services added.

Much of our progress this year can be attributed to the many friends of the ACA. It has been their gifts and support that have shored up any gaps that dared to become too large. We thank the many members, donors and corporate sponsors who have financially supported the ACA these past 12 months.

We look to 2008 with expectations of continued progress, financial achievement, and mission impact. We invite you to join us in our journey.

Best regards,

David McGill

David McGill
ACA Board Chair

There are approximately 1.7 million individuals living with limb loss in the U.S. – that's 1 in every 180 people.

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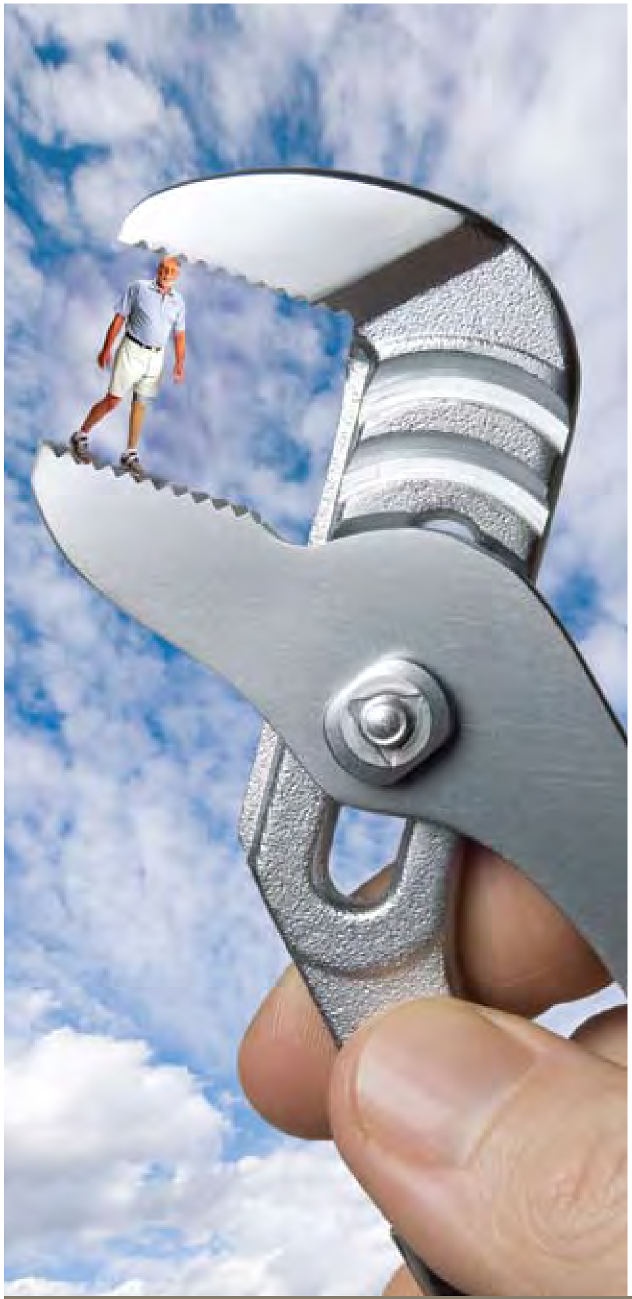
PROGRESS THROUGH ADVOCACY

> *“Don’t wait until everything is just right. It will never be perfect. There will always be challenges, obstacles and less than perfect conditions. So what. Get started now. With each step you take, you will grow stronger and stronger, more and more skilled, more and more self-confident and more and more successful.”*
>
> — Mark Victor Hansen



A Total of 7 States Ensure Fair Access to Prosthetics

Through unprecedented coordination among Amputee Coalition of America regional representatives, support groups, and corporate friends, we passed a prosthetic parity law in Oregon this year for a total of 7 laws passed. Additionally, while advancing this march across the country for state-legislated parity, the ACA also designed the strategy to roll out federal legislation in Congress in 2008.

"This is a real grassroots effort," says Morgan Sheets, ACA's national advocacy director. "Not only did this effort arise from the many voices from our membership across the country, but it has taken efforts from local amputees, their friends, families and healthcare providers to move state legislation forward in their states."

Just last year, the ACA conducted an online survey that put numbers to this growing problem. Those numbers sounded the alarm that a growing number of group and private insurance companies are capping their prosthetic benefit so low that the average working family can't afford a prosthesis and/or they are providing coverage for only one prosthesis per lifetime. The ACA also found that some insurance companies are establishing lifetime caps or eliminating coverage completely. On average, an adult amputee will need a replacement prosthesis every 5 years, and children even more frequently as they grow.

It's Only Fair

"Not only does inadequate insurance impose a financial hardship on families with a loved one who has limb loss," says Sheets, "but it's an issue of fairness. The U.S. Department of Veterans Affairs provides coverage. Workers' Compensation insurance, Medicare and Medicaid provide coverage. Congress has coverage. In fact, we are only asking for what the government is providing seniors and what our Congress members are already getting in their insurance packages.

"Individuals with employer-paid health insurance deserve meaningful coverage for prosthetic care," continues Sheets. "They should be treated as fairly as our members of Congress are treated for prosthesis coverage. We are making our senators and representatives aware of how unfairly health insurers treat their enrollees who need meaningful coverage for prosthetic care and how this treatment is negatively impacting their ability to live full lives."

The ACA developed legislative language designed to ensure that amputees covered by employer-paid health insurance are able to access the prosthetic care they

> *"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."*
> *— Margaret Mead*

need to lead full and independent lives.

“Not only will this legislation give financial relief to individuals and families facing economic barriers to getting a prosthesis, but it will save money in the public and private sectors,” says Sheets. “Additionally, passing this legislation will ensure coverage for the many people who have never thought to ask if their insurance adequately covers limb loss.”

Too few people realize that their health insurance policies might not cover their expenses if an accident, cancer or complications from diabetes strike them. Most people just assume that they’re adequately covered. Perhaps the insurance industry wants them to believe that it is sufficient for insurers to cap coverage at $500, even though a below-knee prosthesis (the most common type needed) costs $5,000 to $8,000. Or perhaps the insurance industry wants them to believe that it is fair for insurers to limit people to one limb per lifetime or to refuse to pay for more than one repair a year.

The insurance industry has testified in state legislatures that its coverage is “good” and has argued that mandating coverage would make premiums more expensive for employers.

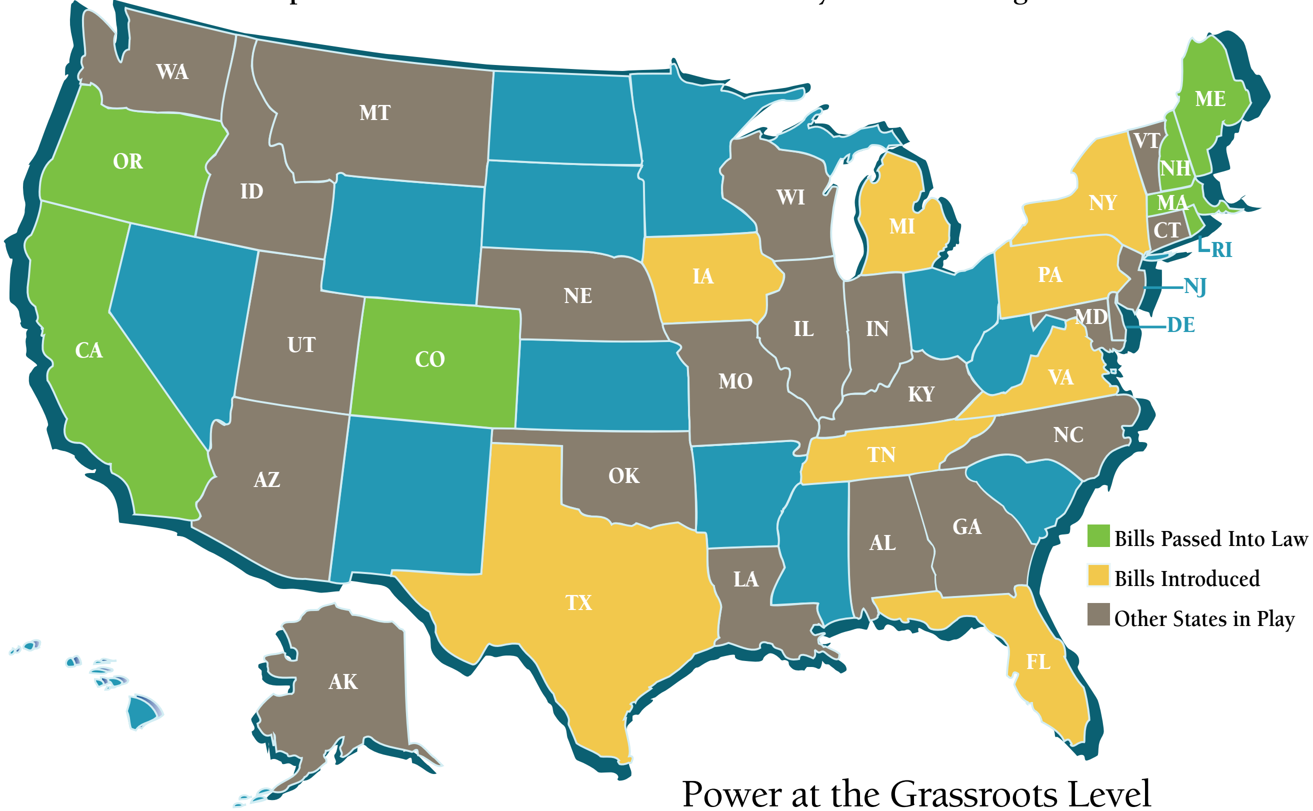
“While limbs are expensive, so, too, are delivering babies, removing tonsils, replacing hips, doing heart catheterizations or running diagnostic scans on a bum back,” says Sheets. “All our legislative language is asking lawmakers to do is support a bill that would require insurers to offer limb loss coverage equal to that offered through Medicare, which is hardly an overly generous program.”

In fact, the ACA collected and analyzed data demonstrating that health insurance parity laws would have a minimal cost impact – only about 12-35 cents more per month – on insurance premiums.

About one-third of limb amputations resulting from cancer involve a lower limb.

Fighting for Appropriate Prosthetic Care

The Amputee Coalition of America's Prosthetic Parity Success Through 2007



Bills Passed Into Law: 7 (CA, CO, MA, ME, NH, OR, RI)

Bills Introduced: 8 (FL, IA, MI, NY, PA, TN, TX, VA)

Other States in Play: 22 (AK, AL, AZ, CT, DE, GA, ID, IL, KY, LA, IN, MD, MO, MT, NC, NE, NJ, OK, UT, VT, WA, WI)

Power at the Grassroots Level

During 2007, the campaign grew to include more than 30 states with a total of 8 considering legislation in their state house.

"We kicked off our parity initiative in 2006 with organizing meetings, and these were very successful," says Sheets. "In fact, these meetings generated momentum that resulted in the passage of 3 bills (Massachusetts, Rhode Island and California) as well as the introduction of 5 new bills in 2007. Tactically, the ACA staff could not be everywhere, so this year, a Web page was developed to more efficiently provide detailed information to those people on the ground in various states. And we began focusing on providing the right tools for our grassroots activists – the real power behind our momentum."

One such activist is Georgia Foltz of Pennsylvania. As a leader in the Pennsylvania Amputee Support Team, she is no stranger to making her voice heard, but her work on HB 2718, her state's bill for prosthetic coverage, has really stood out.

"Insurance caps contribute to many problems for an amputee," says Foltz. "I am happy to be part of the efforts to address these problems in my state."

With sample petitions provided by the ACA in hand, Foltz helped spread the word about the need for prosthetic coverage by asking friends, neighbors and support group members to sign petitions to build an even stronger and farther-reaching campaign. Using a sample "Letter to the Editor" provided by the ACA, Foltz also sent a number of letters to editors, which were published in several newspapers.

"On October 19, Georgia traveled to the Health and Human Services Committee hearing to testify on behalf of the Pennsylvania bill," says Sheets. "With copies of her letter, as well as letters generated by other activists, we were able to demonstrate the strong public support behind this important legislation. This made a definite impact on the elected officials."

Foltz is a dedicated activist and a great asset to the campaign in Pennsylvania. But the truly remarkable thing is that all of the things she has done are activities that anyone who supports prosthetic coverage would be able to do using the various resources that the ACA provides to those who want to get involved.

Onward and Upward

"We have built a national campaign from the ground up," says Sheets. "As of December 2007, we are advancing prosthetic parity in more than 30 states. There are 7 laws on the books, and we are putting the final touches on the language for a federal parity bill to be introduced in Congress in 2008."

The ACA is working with a number of partners to make the parity law a reality at the state and federal levels - partners like the American Board for Certification in Orthotics, Prosthetics and Pedorthics; Hanger Prosthetics & Orthotics, Inc; the Orthotic and Prosthetic Group of America; Ossur; Otto Bock HealthCare, LP; and POINT Health Centers of America.

"Financial support from these organizations and personal support from individuals are critical to us being able to fund national and multistate initiatives against giant insurance companies, such as United Health Group," says Sheets. "It's almost like David and Goliath."

The federal legislation is important, according to Sheets, because certain insurance plans fall under federal jurisdiction.

"We need to pass a law at the federal level in order to impact the coverage available in all private insurance plans," she explains. "The success that we have had at the state level has enabled us to make this bold federal move. We could not have done any of this without the dedication of our funders, coalition partners, and, most important, our hardworking activists."

Approximately 185,000 people in the U.S. have an upper- or lower-limb amputation each year.

Prosthetic Coverage Is Good Medicine for Working Families

Question: Who currently provides coverage for prosthetic devices?
Answer: The U.S. Department of Veterans Affairs and the Department of Defense, automobile insurance, Workers' Compensation insurance, Medicare, Medicaid, the State Children's Health Insurance Program (SCHIP), state vocational rehabilitation and some private insurance polices cover prosthetic devices. The problem is that a growing number of group and private insurance companies cap the benefit so low that the average working family can't afford a prosthesis. Other insurance companies are creating lifetime caps or eliminating coverage completely.

Q: How will state bills change the law?
A: These bills require commercial health insurance carriers to provide coverage for the repair and replacement of prosthetic devices and components. They put prosthetic care on par with other critical medical services.

> *"Progress is impossible without change, and those who cannot change their minds cannot change anything."*
> *— George Bernard Shaw*

Q: What will these bills do?
A: Passage of these bills will ensure that insured working people can continue supporting their families. Additionally, they will ensure that children living without a limb are not forced to spend the rest of their childhood in a wheelchair when help is readily available.

Q: What will this cost the average privately insured individual?
A: Studies have been done in several states, including California, Massachusetts, New Jersey, Colorado and Virginia, and the data has shown that appropriate prosthetic coverage would add only 12-35 cents per month to insurance premiums.

Q: What can a family do when one of its members is recovering from the loss of an arm or a leg and its insurance policy will not cover the cost of a prosthesis?
A: In return for premiums paid for group health insurance, consumers expect to be covered for catastrophic illness or injury. When their insurance coverage is inadequate, families often go into serious debt. They mortgage their homes, get bank loans, or even use college and retirement savings. Some individuals are forced to turn to state Medicaid programs to access coverage.

Q: Is it true that providing prosthetic devices can actually save the state money?
A: Yes! The public sector will see cost savings because appropriate private insurance coverage prevents cost-shifting to the public sector. Cost savings can also be expected in unemployment insurance, state employment and training programs, rehabilitation and counseling programs, and other social welfare systems. It is estimated that every dollar spent on rehabilitation, including prosthetic care, saves more than $11 in disability benefits.

Benefits also include a reduction in the expensive secondary health conditions caused by a sedentary lifestyle, less dependence on caregivers, and a lowered risk of diabetes-related complications that can lead to additional amputation. In addition, this segment of the population can continue to be contributing members of society instead of becoming dependent on it.

PROGRESS THROUGH VOLUNTEERISM

> *"Nothing liberates our greatness like the desire to help, the desire to serve."*
>
> — Marianne Williamson

Outreach Means Going Beyond

One of the definitions of "outreach" is "to go beyond," and the great contributions in time, effort and commitment of our volunteers are taking the ACA to an entirely new level of possibility for reaching those who need our help.

The backbone of any successful nonprofit consumer organization is formed from the passionate visions of its volunteer constituents. Those who were helped in their time of greatest need are driven to give back, and those who were unable to find support elsewhere often become determined to spare others a similar experience.

As a national organization, the ACA is still very young and relatively small in its budget and staffing. Yet, it has an enormously large commitment to bring all of its resources to bear in reaching the individuals and families of people with limb loss and limb differences all across the country. This is a Herculean effort as there are approximately 1.7 million Americans with limb loss, many of whom know nothing of the ACA. These individuals and their families, friends, religious and spiritual advisers, lawyers, healthcare providers and other support systems need to know how much help is available from this nonprofit organization, which was organized by and around people with limb differences.

To both harness the energy of its eager volunteers and to reach into more local communities to raise awareness of the ACA's mission and available resources, the ACA hosted its first Volunteer Outreach Team (VOT) training in November. Eight regional representatives and 14 other volunteers from across the country attended this intensive 3-day event. All except one of the trainees were people with limb loss.

At the training, VOT members had a chance to meet all of the Knoxville staff, tour the ACA offices, and learn more details about the work of the ACA. Many topics were covered, including how calls are handled at the call center and what sources of information can be accessed through the ACA Web site and online library resources. The team members also learned how information is tailored for different audiences and what the Youth Activities Program is doing to provide more camp opportunities for children with limb loss and limb difference.

> *"There are two ways of spreading light – to be the candle or the mirror that reflects it."*
>
> — *Edith Wharton*

Volunteer Outreach Team 2007 Graduates

George Austin
Annabel Burch
Ralph Fowler
Ryan Leishman
Lise Lindsay
Marifran Mattson
Randy Mecca
Jan Morrissey
Dick Nickle
Marianne Rankin
Neil Seigfried
Kathy Spozio
Woody Thornton
Lori Timms

Participants at the VOT training spent one of the mornings in small groups practicing delivering presentations as if to different audiences. For example, some spoke as if they were talking to a support group, others to a civic club or at a hospital in-service.

Back in their own communities, not all VOT graduates will be doing the same things. Their differing activities will depend upon their schedules, interests and special skills, as well as the ACA's identified needs in their geographic areas. Some, for example, will represent the ACA through booths at health shows, such as the American Diabetes Association's Diabetes Expos, area O&P events, or local health fairs. Others may work with local media to use their stories to achieve more public awareness. Still others may encourage prosthetists who are not yet members to join the ACA for the benefit of their patients. Some also expressed interest in developing small fundraising events to help send people with limb loss to the ACA's Annual Conference.

Our deepest appreciation and heartfelt thanks goes to our VOT graduates.

Photo by Fred W. Baker III

Peer Amputee Volunteer Puts Experience, Compassion Into Recovery

by Fred W. Baker III, American Forces Press Service

An admitted golf "nut," Jack Farley said he has heard probably every handicap joke there is, having hit the green for the last four decades wearing a prosthetic right leg. Still, nobody cuts him any slack, he said.

"I try to get strokes for this and nobody will give me any strokes," Farley said and laughed.

Farley is a peer amputee visitor at Walter Reed Army Medical Center here. A retired federal judge, Farley is quick with a joke and a smile. He knows nearly everybody at the center it seems and knows nearly everything there is to know about prosthetics.

His right leg was claimed by a mortar in Vietnam nearly 40 years ago. He was fitted for his first prosthesis at Walter Reed. It was there, on a blind date, that Farley met the woman who would later become his wife. It was there he started a new life. If he hadn't lost his leg, Farley said, he wouldn't have returned to college to study law and subsequently would not have become a federal judge. It is only fitting, Farley said, that he returns to help others.

"It's a sense of paying back. I had mentors and people visiting me when I was here in Walter Reed in 1969 and '70," he said. "I get more out of it than they do. It's a real selfish act on my part."

The peer visitor program began four years ago at Walter Reed when, due to the war in Iraq, an influx of amputees started entering the hospital system. It began with a small group of amputees experienced in visiting and listening and helping new amputees and has grown into a formal program offering training and certification. Peer amputee visitors are considered part of the treatment team at the center. They have access to every floor.

"In the beginning our job is just to listen. I don't come in and say, 'Hey, look at me," Farley said. "The peer visitor comes in and just tries to deal with the family and deal with the patient, explaining that life is going to be different, but whether it's better or worse it's still up to the patient."

On this visit, Farley talked with Marine Lance Cpl. Josh Bleill, who lost both legs in Iraq when the Humvee in which he was riding struck a bomb. It killed two fellow Marines, one riding to the front and one to the left of him. The gunner lost his right leg. Remarkably, the driver was uninjured and is still serving in Iraq, Josh said.

Josh was getting a new socket, the piece of the prosthetic leg in which the residual portion

Jack Farley in Vietnam, 1960s

of the leg fits. New bone growth in Josh's leg rubbed against his old socket, causing pain.

Wearing a pair of khaki shorts, Farley sported a star-spangled socket – blue with white stars, just like an American flag. It is the most important piece of the prosthetic leg, he said.

"You can put a million dollars in technology below the socket, but if it doesn't fit right or is uncomfortable, nobody is going to wear it," he said.

Josh said Farley's experience sometimes helps him explain things to the doctors and technicians that are hard to put into words.

The peer visitor program consistently receives the highest ratings from patients at the center, he said.

"It's a great program," Josh said. "It's nice to see when you are first injured that there is life after this."

Farley said his role changes during the progress of the amputee. Each goes through five stages: enduring, suffering, reckoning, reconciling and normalization.

For many, though, there is a sixth stage – thriving, Farley said.

"You'll see people who actually accomplish more having gone through the trauma … than they would without it," Farley said.

"I wouldn't have gone to law school. I already had an MBA. I was going into business. I would have never been a lawyer, much less a federal judge," Farley said. "By overcoming this in a positive way, it actually can assist you in other challenges in life."

Farley said that some younger service members resist help at first. He told the story of a young man who was trying to do everything himself, resisting the helpful efforts of a new bride.

"He wanted to do everything himself," Farley said. "One day I just pulled him aside and said, "You know, the greatest gift of love you can give is to maybe allow somebody to help you."

Later on, we all realize we need the help of everybody," he said.

> “*You know, the greatest gift of love you can give is to maybe allow somebody to help you.*”

PROGRESS THROUGH PROGRAM ADVANCEMENTS

"The greatest thing in this world is not so much where we stand as in what direction we are moving."

— Johann Wolfgang von Goethe

CDC Extends Agreement With ACA

In 2007, the ACA announced a $6.6 million, 4-year continuation of funding from the Centers for Disease Control and Prevention (CDC) for the ACA's National Limb Loss Information Center (NLLIC). The NLLIC provides comprehensive resources for people with limb loss, as well as their families, friends, and the health-care professionals involved in their lives.

"The programs of the ACA have had an enormous impact on the limb loss community, and the support of the CDC reflects that," says Paddy Rossbach, ACA president and CEO. "Our relationship with the CDC spans more than a decade, and their ongoing funding has enabled us to answer the needs of the almost 2 million Americans living with limb loss or limb difference."

NLLIC activities for program years 2007-11 will focus on the following priorities:

- Disseminating and evaluating limb loss educational materials
- Conducting national outreach through the development and dissemination of materials, support, programs and services
- Disseminating and evaluating materials and programs targeting social and emotional needs
- Developing and disseminating prevention messages through collaboration with other organizations
- Developing and maintaining organizational partnerships to support these initiatives
- Monitoring and evaluating programs, services and activities.

> *"The programs of the ACA have had an enormous impact on the limb loss community, and the support of the CDC reflects that."*

Promoting Amputee Life Skills Moves Forward: From PALS to PALS Plus

Johns Hopkins University (JHU) Schools of Public Health and Medicine and the University of Washington (UW), in collaboration with the ACA, developed PALS (Promoting Amputee Life Skills) as an 8-week self-management program to help people with limb loss develop skills to improve their lives.

The program takes place in a group setting with people working together to learn and practice self-management skills, such as problem solving. PALS recognizes that people with limb loss have a lot to teach each other, and it builds on each individual's strengths as he or she learns new skills.

Topics included in the self-management course include managing limb-loss-related pain, increasing positive mood, developing coping skills, and communicating with the healthcare team. Participants also learn skills to help them improve interactions with their family and friends and to boost their ability to network and problem solve.

The research team of JHU, UW and the ACA, sponsored by the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, completed a national study evaluating PALS. The study results were very positive:

- 95 percent of participants would recommend PALS to a friend.
- 77 percent indicated that PALS provided important help beyond the help they received from a support group.
- More than 50 percent rated PALS as more important than other services provided to them since their amputation.

The research results also showed that those who participated in PALS had a reduced chance of being depressed, increased their confidence in managing amputation-related problems, increased their positive mood, and were less likely to experience limitations in function compared to those who only participated in a support group. While the entire group of amputees who participated in PALS benefited, those who participated during the first 3 years following their amputation had greater benefits than more experienced amputees.

"We believe this is the largest clinical trial ever completed with amputees," says Stephen Wegener, PhD, one of the study investigators from the Department of Physical Medicine and Rehabilitation at JHU School of Medicine. "The success of the project is due to the support and participation of amputees and support groups. Those folks helped us develop the PALS program and enthusiastically supported the study. We believe PALS is successful because it helps build specific skills, empowers people to take control, and focuses on strengths rather than weaknesses."

Building on the success of PALS, the JHU and UW team, again working with the ACA, has started a new project: PALS Plus. The goal of this project, which is funded by the CDC, is to improve the outcomes from PALS alone by adding peer visitation and delivering this combination of services in the first 9 months following amputation.

While the PALS Plus program is limited to certain locations, the ACA is rolling out the regular PALS program across the country. There are now more than 50 certified PALS trainers across the country who are prepared to offer the classes.

> "*We believe PALS is successful because it helps build specific skills, empowers people to take control, and focuses on strengths rather than weaknesses.*"

From Camper to Counselor at the ACA Youth Camp

The ACA Youth Camp helped Jamal Maccou get back on solid footing, and now he is helping other children and teen-agers do the same. Between Christmas Day and New Year's Eve in 2000, an automobile accident resulted in the amputation of Maccou's left leg above the knee. In the painful and trying years of rehabilitation that followed, he made a great deal of progress but never felt like his old self.

"When the accident first happened, my confidence was pretty low," says Maccou, 18, who lives in Illinois. "I felt like an outsider."

That all changed 5 years ago when Maccou took part in his first ACA youth camp, where he found he was no different from anyone else. After 4 years as a camper, he returned in 2007 as a junior counselor for 5 days of nonstop action and activities from July 18-22 at Camp Dream in Warm Springs, Georgia.

"I love this camp," Maccou says. "As the first year at camp progressed, I realized that [limb loss] wasn't anything that was really going to slow me down."

More than 60 children with limb differences between the ages of 10 and 16 converged on the camp from 26 states across the country this year. In its 8th year, the ACA Youth Camp, run by the Youth Activities Program (YAP), offered a wide variety of physical and recreational activities and team-building exercises, including wheelchair rugby, basketball, swimming and canoeing.

Golf and tennis were introduced this summer, but the camp is more than just fun and games. Educational sessions concerning nutrition and informal support group meetings are also offered, as are chances to learn from peers and adult amputee mentors.

Kimmie Champion, who says she has "the best last name ever," heard about the camp from her prosthetist and made her first trip there last summer. Champion was immediately hooked, mainly because she enjoyed working with the younger campers but also because it was her first experience of being surrounded by others with limb differences.

"It was a little unusual at first," says Champion, 18. "Other than my prosthetist, I only know one other girl with a prosthesis in my town [in

More than 1,000 children are born with limb difference each year.

On average, more than 600 children lose a limb to a lawn mower each year.

Georgia]. Last year, as a camper, I fell in love with the younger girls. That's what I like most, to help the little girls learn something."

YAP coordinator Derrick Stowell, MS, CTRS, said he found a perfect mix of working in the outdoors and mentoring children when he joined the ACA and YAP in September 2006. Although he enjoys watching the campers work their way through the various activities, it is the friendships that are forged and the lines of communication that are opened that matter most.

"The biggest part is the interaction with other amputees," Stowell said. "Some children might not know another amputee until they come here."

In 2007, the ACA Youth Camp was sponsored by Ohio Willow Wood, Otto Bock HealthCare, and the restaurant chain Denny's, and was partially funded by the Centers for Disease Control and Prevention and ASPIRE (Adolescent Sarcoma Patients' Intense Rehabilitation with Exercise). The camp began in 2000 as the Youth Initiative, a satellite program offered at the ACA Annual Conference. Since then, it has grown into a 6-day event, including travel days for the campers and training sessions for the counselors that bookend a series of outdoor activities.

ACA's 2007 Annual Conference Draws Record Number of Attendees

A record number of people attended the 2007 ACA Annual Conference held June 15-17 at the Renaissance Waverly Hotel in Atlanta, Georgia. The 818 participants included 306 first-timers and represented 42 states and 6 countries.

The 2007 conference debuted sessions on traveling with a disability, solutions and technology updates related to each amputation level, swimming for fitness, and federal employment strategies for people with disabilities. The conference received an almost perfect score from participants with evaluation ratings of excellent or good at 95 percentile.

The 2007 ACA Awards of Excellence were announced, and Sean Brame, William Samuels and Dennis O'Donnell were among this year's recipients. Brame, Samuels and O'Donnell received awards in recognition of the work they have done to advance the ACA and our prosthetic parity initiative.

Sean Brame received the ACA Role Model of the Year Award. This award recognizes the power that one person's positive influence can have on other individuals and is given to an amputee who has inspired, mentored or otherwise helped ACA members or other individuals in the amputee community.

At age 9, Brame became a quadrilateral amputee from septic shock, following an ankle injury while playing soccer. Less than a year after losing his limbs, Brame rejoined his soccer team. He is also very active in his local support group, was recently trained as an ACA peer visitor, and has played a large role in advancing prosthetic parity in Pennsylvania. He testified at a legislative hearing in fall 2006, spoke at a press conference and rally at the Pennsylvania Capitol in April, and has acted as a spokesperson for prosthetic parity at many other events.

William Samuels received the ACA Volunteer of the Year Award. This award is given to an individual in recognition of his or her dedication and commitment of personal time, resources or skills to reach out to ACA members or others in the amputee community.

Samuels is the co-founder and facilitator of Out On A Limb — Memphis Area Limb Loss Support. Samuels is not only responsible for running his own highly successful support group but has also helped other support group leaders with resources and advice.

He is also an ACA-certified family visitor and has been a big part of the effort to advance prosthetic parity in Tennessee. In fact, the Memphis group hosted one of the first ACA parity organizing meetings last summer.

Dennis O’Donnell received the ACA Advocate of the Year Award. This award is given to an individual who has made significant contributions

to the ACA's national campaign for prosthetic coverage through involvement in our state-by-state effort to raise awareness, build support and advance legislation.

O'Donnell is a bilateral above-knee amputee. He has firsthand experience with insurance issues and spent his first 2 years as an amputee in a wheelchair. The private insurance that he had at the time did not have sufficient prosthetic coverage to provide him with the prostheses that would enable him to walk. When O'Donnell became eligible for Medicare, he was fitted with appropriate prostheses and has now returned to work.

These experiences led him to work tirelessly to push the parity bill forward in New Jersey. O'Donnell has also enabled and encouraged other amputees and their family members to get involved in the fight for parity. He has initiated letter-writing campaigns, started an online petition, and single-handedly collected more than 2,000 signatures for the ACA's "10 in 10" campaign.

Parent Survey Leads to Changes in Parent Support Network

Whatever the cause, and however the news is received, parents are universally devastated to learn that their child must deal with limb loss or difference. They doubly mourn – over the loss of their natural expectations of having a "normal" child grow into a "normal," healthy adult and for their child who isn't yet able to grasp all of the implications for his or her future. Under these circumstances, massive doubts arise in parents about their ability to become the parents their child needs them to be. These parents have special needs.

Charlene Whelan, LCSW, MBA, Laura Willingham, and Lourdes Talan, a social worker at Shriners Hospital for Children – Twin Cities, conducted in-depth interviews with a number of parents of children with limb loss or limb difference. During their interviews, they asked parents what they found helpful along their path of adjustment and when and how that support was provided. They also asked about obstacles to their adjustment.

One parent, Leigh, who was interviewed for a story in *inMotion,* reflected on her past 10 years as a mother of an amputee, saying, "It wasn't until I supported another parent that I realized how far I had come. After visiting with another mother going through what I had been through, I realized how invaluable that support is, because so many of the feelings you have as a parent in this particular situation are almost indescribable to anyone else. Connecting with another parent dealing with amputation – it's like speaking in a special language of comfort. I kept thinking about how much I wished I had that during my time of need."

The data from these interviews revealed that while having the option of a peer visit is important for an adult soon after amputation, or even beforehand if possible, it is even more crucial to the alleviation of a parents' massive anxiety in this time of crisis. Parents said that being contacted soon and being matched up with parents who faced the same circumstances are far more important than the method of contact.

This interview data identified needed changes in the ACA Parent Support Network (PSN). Starting in 2008, after reviewing the results from 2 field tests, we will begin conducting national training programs to certify parents who are willing and able to volunteer their time to give PSN support to other parents.

More than 25,000 children are living with limb loss today.

ACA Partners With Wounded Warrior Project

Training peer visitors at Naval Medical Center San Diego

In a collaboration designed to expand peer visitation within military medical centers, the ACA partnered with the Wounded Warrior Project (WWP) to conduct a “Train the Trainer” seminar and a peer visitor seminar at the Naval Medical Center San Diego (NMCSD).

The WWP funded the training and provided valuable input for revising the ACA’s peer visitor materials to meet some of the additional needs of wounded soldiers. The revised manual contains information on providing support for wounded personnel with traumatic brain injury, hearing loss, vision loss and burns. Additional manual enhancements include protocols for working effectively with caregivers, procedures for reporting peer visits, and role-play activities that give participants experience in providing effective peer support.

WWP staff member Lonnie Moore, an ACA/Walter Reed Army Medical Center peer visitor, was certified as a peer visitor trainer at the seminar. Major Jacqueline Coley, Dave Rayder and Paralympic gold medalist Casey Tibbs were also certified as trainers by Patricia Isenberg, certified master trainer and ACA chief operating officer.

The group of new trainers conducted a 1-day peer visitor seminar on April 27 and certified 11 new military peer visitors and one family visitor. The new peer visitors will be called upon by the care team at the NMCSD's Comprehensive Combat Casualty Care Center (C5).

C5 is the military's first and only center for amputee care in the western U.S. It provides orthopedics, prosthetics, physical and occupational therapy, wound care, psychiatric care, brain injury care and mental health services. A new facility is under construction to house C5's services, which are currently spread throughout the medical center.

ACA Debuts New Publication:

SideStep – A Guide to Preventing and Managing Diabetes and Its Complications

Nearly 21 million children and adults in the U.S. live with diabetes, and another 54 million are considered pre-diabetic. In 2002 alone, diabetes cost our country $92 billion in direct medical costs. It is also a leading cause of lower-limb amputations.

While diabetes is one of the most invasive diseases, it is also manageable. ACA created *SideStep* for those at risk for diabetes and those who have the disease, are suffering from its complications, or care for someone with the disease.

By reading *SideStep*, readers will learn the following and much more:

- What diabetes is and how the various types differ
- Diabetes' risk factors and how to avoid developing the disease
- The ABCs of managing diabetes
- How to reduce the risk of developing diabetes-related complications
- How to deal with diabetes-related complications.

The risk of amputation increases substantially as people grow older, mostly due to diabetes and peripheral vascular disease.

Each year, more than half of all amputations in the United States are caused by diabetes mellitus and subsequent complications. Most of these are lower-extremity amputations.

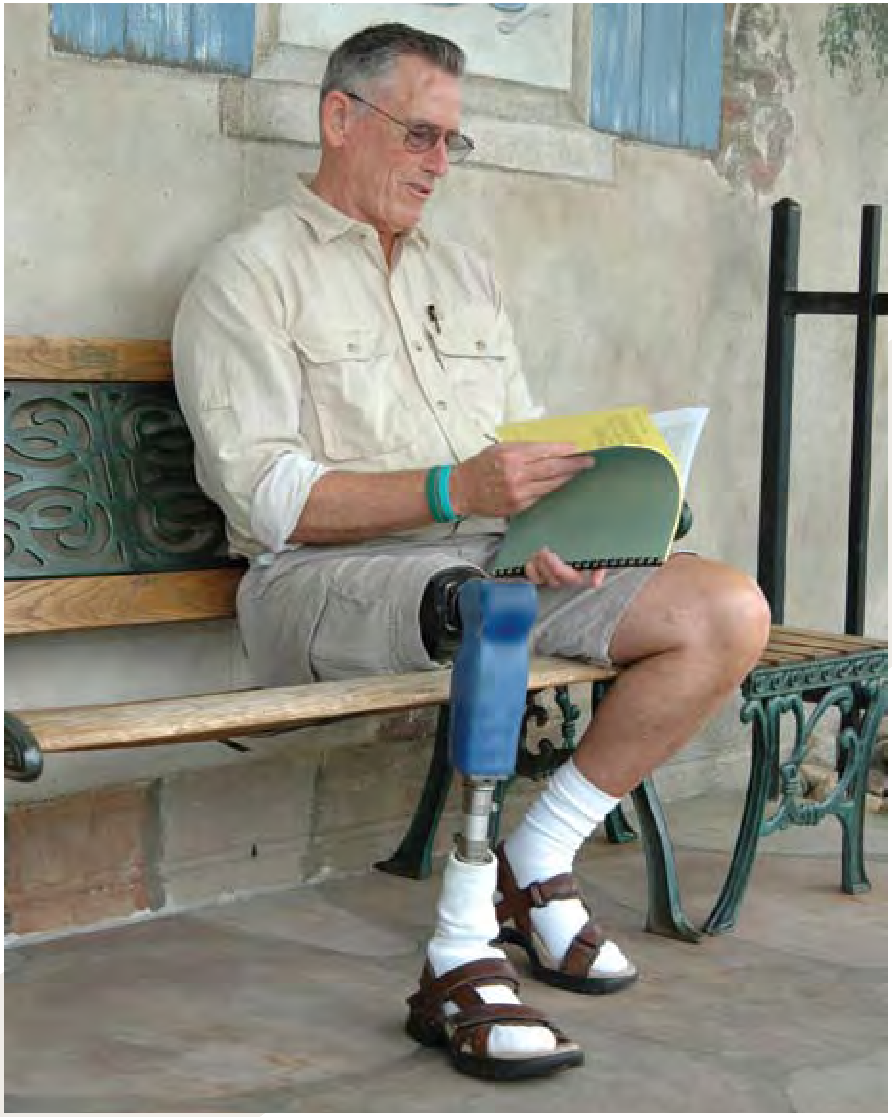
Comprehensive amputation prevention programs could reduce amputation rates by 50 to 69 percent and save up to $8 billion per year.

Expenditures for amputations in people with diabetes are estimated at approximately $11.7 billion per year.

PROGRESS THROUGH MEASUREMENT

> *"It does not matter how slowly you go so long as you do not stop."*
>
> *— Confucius*

The Amputee Coalition of America (ACA) is a nonprofit organization and the national leader in developing and disseminating limb loss information, including information on best practices in clinical improvement and care management. In 2007, the ACA analyzed the effect of our various outreach initiatives and documented the following impact:



Lives Benefited

New Amputee Contacts	112,328
Number of ACA-Certified Peer Visitors	961
Number of Peer Visits Reported	3,160
Fact Sheets Distributed	42,000
Web Site Visits	2,500,000
Unique Web Site Visitors	364,000
Annual Conference Attendance	818
Support Groups	273
Youth Campers	81

Community Outreach

Every year, the ACA conducts and participates in educational outreach and educational activities.

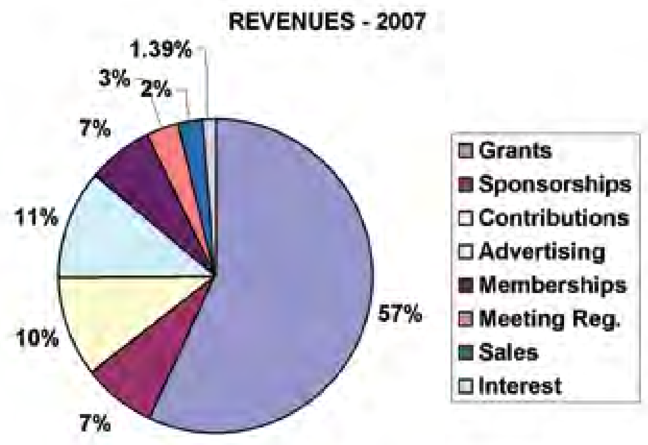
National, Regional, Local Exhibits	34
National/Regional Presentations	30

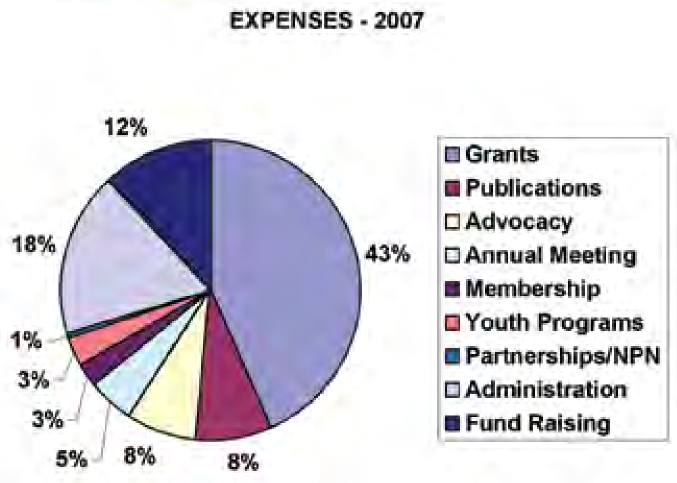
The People of the Amputee Coalition of America

Board Members	9
Total Employees	33
Regional Representatives	9
Volunteers	1,400
Medical Advisory Committee Members	14

FINANCIAL SUMMARY

The ACA had a net loss of $86,535 in 2007 because of investment in new programming.





Sources of Funds	
Grants/Contracts	$1,777,903
Memberships	$209,743
Corporate Sponsorships	$230,540
Development	$321,771
Other Sources	$580,615
Total	**$3,120,572**
Uses of Funds	
Salaries, Fees and Fringe Benefits	$1,450,380
Programs and Services	$1,427,181
Net Building, Equipment and Working Capital	$23,789
Rent, Insurance, Maintenance and Other Business Expenses	$244,197
Other Payments	$61,560
Total	**$3,207,107**

FINANCIAL REPORT

The Amputee Coalition of America (ACA) is a nonprofit organization established as an educational resource to promote amputee awareness and understanding throughout the United States. The ACA's primary funding sources are federal grants, memberships, publication advertising, sponsorships, an annual conference and donor contributions.

The financial statements of ACA have been prepared by the independent audit firm of Coulter & Justus, P.C., in accordance with accounting principles generally accepted in the United States of America and provide for the accrual basis of accounting.

STATEMENT OF FINANCIAL POSITION

	December 31 2007	 2006
Assets		
Current assets:		
Cash and cash equivalents	**$ 769,885**	$ 913,485
Accounts receivable, net of allowance for doubtful accounts of $2,750 in 2007 and 2006	**33,320**	31,777
Contributions receivable	**104,051**	47,500
Grants receivable	**168,228**	159,503
Prepaid expenses	**-**	1,017
Total current assets	**1,075,484**	1,153,282
Equipment and furniture	**347,625**	307,149
Leasehold improvements	**11,937**	-
Less accumulated depreciation	**(314,116)**	(306,911)
Net property and equipment	**45,446**	238
Other assets	**3,332**	3,332
Total assets	**$ 1,124,262**	$ 1,156,852
Liabilities and net assets		
Current liabilities:		
Accounts payable	**$ 49,596**	$ 45,794
Accrued expenses	**91,582**	63,926
Current portion of deferred membership revenues	**115,807**	95,702
Total current liabilities	**256,985**	205,422
Deferred membership revenues, net of current portion	**38,948**	36,566
Total liabilities	**295,933**	241,988
Net assets:		
Unrestricted	**724,278**	914,864
Temporarily restricted	**104,051**	-
Total net assets	**828,329**	914,864
Total liabilities and net assets	**$ 1,124,262**	$ 1,156,852

STATEMENT OF ACTIVITIES

	Year ended December 31, 2007			Year ended December 31, 2006		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Support and revenues:						
Grants	**$ 1,777,903**		**$ 1,777,903**	$ 1,757,670		$ 1,757,670
Sponsorship contributions	**126,489**	**$ 104,051**	**230,540**	79,070		79,070
Contributions	**321,771**		**321,771**	281,438		281,438
Publication advertising	**355,289**		**355,289**	343,312		343,312
Memberships	**209,743**		**209,743**	170,637		170,637
Educational material sales	**75,189**		**75,189**	46,015		46,015
Training income				2,368		2,368
Annual meeting	**106,694**		**106,694**	80,410		80,410
Interest income	**43,443**		**43,443**	23,368		23,368
Net assets released from restrictions				68,552	$ (68,552)	
Total support and revenues	**3,016,521**	**104,051**	**3,120,572**	2,852,840	(68,552)	2,784,288
Expenses:						
Program services	**2,252,904**		**2,252,904**	2,137,294		2,137,294
Supporting services	**954,203**		**954,203**	585,894		585,894
Total expenses	**3,207,107**		**3,207,107**	2,723,188		2,723,188
Change in net assets	**(190,586)**	**104,051**	**(86,535)**	129,652	(68,552)	61,100
Net assets at beginning of year	**914,864**		**914,864**	785,212	68,552	853,764
Net assets at end of year	**$ 724,278**	**$ 104,051**	**$ 828,329**	$ 914,864	$ -	$ 914,864

STATEMENT OF FUNCTIONAL EXPENSES

	Year ended December 31, 2007			**Year ended December 31, 2006**		
	Program Services	**Supporting Services**	**Total**	**Program Services**	**Supporting Services**	**Total**
Operating expenses:						
Salaries	**$ 800,537**	**$ 233,763**	**$ 1,034,300**	$ 744,766	$ 151,376	$ 896,142
Benefits	**322,041**	**94,039**	**416,080**	284,396	55,512	339,908
Supplies	**133,099**	**31,925**	**165,024**	63,341	20,551	83,892
Travel	**353,526**	**45,179**	**398,705**	300,204	43,461	343,665
Contractual costs	**252,979**	**259,609**	**512,588**	352,967	105,921	458,888
Minor capital costs		**16,584**	**16,584**		16,672	16,672
Educational resources	**20,970**		**20,970**	22,569	6,319	28,888
Printing	**179,130**	**6,922**	**186,052**	179,821	15,192	195,013
Postage	**128,303**	**15,539**	**143,842**	109,731	8,604	118,335
Communications	**16,922**	**18,475**	**35,397**	10,319	14,545	24,864
Rent	**20,466**	**148,975**	**169,441**	33,319	77,336	110,655
Repairs and maintenance		**11,377**	**11,377**		15,816	15,816
Insurance		**10,466**	**10,466**		13,034	13,034
Utilities		**17,516**	**17,516**	2,389	8,898	11,287
Depreciation		**7,205**	**7,205**		3,360	3,360
Commissions	**3,000**		**3,000**	14,528		14,528
Other	**21,931**	**36,629**	**58,560**	18,944	29,297	48,241
Total operating expenses	**$ 2,252,904**	**$ 954,203**	**$ 3,207,107**	$ 2,137,294	$ 585,894	$ 2,723,188

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$25,000 - $100,000
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$10,000 - $24,999
Cushman & Wakefield
Denny's, Inc.
POINT Health Centers of America, Inc.

$1,000 – $9,999
Active Amputee Support Group
ASPIRE
Bela & Catherine Schick Foundation, Inc.
Cohn & Wolfe
Crockett Prosthetics & Orthotics
Drew Shoe Corporation
Finish Line Youth Foundation
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My Kids Media, Inc.
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