



amputee  
coalition™

saving limbs. building lives.



*Impact...for Life*

*" I have found that in the simple act of living with hope, and in the daily effort to have a positive impact in the world, the days I do have are made all the more meaningful and precious. And for that I am grateful."*

— Elizabeth Edwards, July 3, 1949—December 7, 2010

# *Impact...for Life*

*Impact for Life* was selected as the theme for the Amputee Coalition 2010 Annual Report because it epitomizes the collective efforts of the organization to provide programs, services and resources to amputees, families and those at risk for limb loss not only over the course of their lives, but also to help them "get their lives back" after amputation. The 2010 Annual Report team invites you to enjoy the stories and information in this year's report.

## 2010 ANNUAL REPORT TEAM

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**FRONT COVER** Aaron Holm with his wife and son. *Thank you to Otto Bock HealthCare for providing front cover photo.*

# Leadership Message

When we accepted the leadership roles of the Amputee Coalition, it was with the understanding that limb loss wouldn't wait for us to ease into these positions. Every day, 507 amputations are performed in this country—so the mission we have is an urgent one. We had to keep in mind the large number of people at risk for limb loss—more than 20 million—but however daunting that number, we must never lose sight that we are serving individuals living with limb loss, each with their own struggle.

We developed our 2015 Plan which is underpinned by our mission: ***to reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention.***

We do this through funding support services, education and outreach; we do this by fighting for fair insurance for prosthetic devices and for more adequate funding for prevention and care; we do this through our programs to improve the lives of those affected by limb loss; and we do this by raising awareness about the impact of limb loss.

We know limb loss makes a huge impact on individuals and is also a cost burden to the health care system. This year, we funded the first Limb Loss Task Force Summit which developed a Four Point Action Plan that is now our roadmap to improving care for amputees and impacting limb loss prevention.

Our advocacy efforts are very important for our constituency. This year, we celebrated some advocacy victories, especially at the state level. In Utah, legislation was signed that will help ensure that amputees have access to fair insurance coverage for prosthetic devices. This same language was introduced in nine states and in Congress.

Without information, those affected by limb loss can be at a disadvantage. Therefore, the Amputee Coalition offers those affected by limb loss the best information and tools available. Our National Limb Loss Resource Center answers questions and delivers information to thousands of callers each year.

Our Web site, [www.amputee-coalition.org](http://www.amputee-coalition.org), helps more than 400,000 visitors a year find the information they need.

A special accomplishment this year was the doubling of the number of campers attending the Amputee Coalition Paddy Rossbach Youth Camp. This achievement was made possible by the many donors who supported the camp and felt passionate about reaching more children living with limb loss/difference. This camp provides them a safe environment to learn and share information about living with limb loss.

Our relationship with our donors is very special and unique in many ways. We often encounter amputees who want to “move forward by giving back.” This attitude and desire among amputees and people impassioned by our work are crucial to the sustainability of our programs and services. The impact we make, and the impact we have the potential to make in the limb loss community and in the nation, is directly related to the level of support and resources we have available.

The theme for this Annual Report is, ***“Impact...For Life.”*** That describes both living with the loss of a limb and the work done by the Amputee Coalition. We are the leader in the field of living with limb loss and our credibility and impact is unrivaled. But we never forget that, although we serve everyone affected by limb loss, “everyone” is comprised of many different individuals with their own stories of heartbreak and triumph in the fight to get their lives back.

As you read the stories in this Annual Report, you will see firsthand why we continue to live out our mission.



Marshall Cohen  
Chair, Board of Directors



Kendra Calhoun  
President & CEO

## Overview

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The loss of a limb can be emotionally and physically devastating. The Amputee Coalition's Certified Peer Visitor Program was established on the important premise that contact with others who are affected by limb loss is crucial, especially for new amputees. Our Certified Peer Visitor program includes an active national team of volunteer visitors, all of whom have personal experience as an amputee, as a caregiver or as a parent of an amputee child. Our program matches experienced, well-trained peers with new amputees based several key criteria like level of amputation, age, gender. The visit, which can be conducted in-person, by phone or email, is confidential, but provides the amputee or family member with key resources and contacts to support them through recovery and readjustment.

The Amputee Coalition Certified Peer Visitor Program has certified more than 1,000 peer visitors since 2001.

## Outcomes

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- 154 Amputee Coalition Certified Peer Visitors.
- 6,427 peer visits reported in 2010.

## Future Goals

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- Perform a needs assessment of the program.
- Integrate peer visitation into hospitals and clinics.
- Increase awareness about peer visitation through healthcare provider relations.
- Integrate the Amputee Coalition Certified Peer Visitor Program into the Veteran's Administration Amputation System of Care.

## Amputee Coalition Peer Visitor Program A New Normal

I was one of the 2 million amputees fighting to get my life back—to a “new normal.” I was at the end of my rope. I didn't know what to do next. I was having bad thoughts that scared me. I didn't see any other way to get my life back, so I was thinking I might as well end it.

I am a below-knee amputee. I had no support, nobody to talk to that understood how I felt and or what I was going through. In my mind, my life was over. Then I found the **Amputee Coalition Peer Visitor Program** and requested a peer visit. From the moment I met Bill Nessel, my Amputee Coalition Certified Peer Visitor, I knew I could get to a new normal. He gave me hope and confidence that I could get my life back. I am glad I decided to try one last thing to find help. The Amputee Coalition literally saved my life.

*“Through this amazing organization, I have found friends, support groups, information... I recently became a... Peer Visitor because I want to ‘pay forward’ the support and connections... that helped me get my life back.”*

Through this amazing organization, I have found friends, support groups, information. Now I am organizing, with help from the Amputee Coalition, a support group in Spanish, since limb loss is very prevalent in the Hispanic community. I recently became an Amputee Coalition Certified Peer Visitor because I want to “pay forward” the support and connections through the Amputee Coalition that helped me get my life back.

Bill Nessel and Luis de Leon met as a result of peer visiting and Luis is now helping others as a peer visitor.



## Overview

The Amputee Coalition's state by state effort to change the coverage practices of the insurance industry to provide fair coverage for prosthetic and orthotic care not only helps those in the states where laws have been enacted, but builds momentum for passage on the federal level.

In addition to insurance fairness, the amputee coalition has been working on behalf of amputees who are traveling through America's airports to secure their rights as they interact with the Transportation Safety Administration.

Assuring safe and quality care by supporting state licensure laws for prosthetists and orthotists has also been a goal of the Amputee Coalition's advocacy program during 2010.

## Outcomes

- 19 states that have passed the fair insurance bill.
- 9 states that have introduced the fair insurance bill.

## Future Goals

- Inclusion of prosthetic and orthotic coverage in the federally required "essential benefits set" for insurance companies.
- Prevent coverage erosion for prosthetics and orthotics in state Medicaid programs.
- Continue efforts to pass insurance fairness legislation on the federal level and in the remaining thirty one states.
- Ease travel and mobility issues for amputees.
- Maintain CDC funding.

# Amputee Coalition Government Relations Making a Difference

Tami Stanley never dreamed of taking on insurance companies or the state legislature—but she did after she became impassioned about making sure amputees in Utah have access to fair insurance coverage.

"I was shocked and disheartened to learn that insurance policies may not cover the cost of a prosthesis and I became determined to help give amputees a voice to get a solution through the state legislature," said Tami. Working with the **Amputee Coalition Government Relations** team, Tami became the lead amputee advocate in Utah. Through her hard work and persistence, the Utah State Legislature passed and the Utah Governor signed into law the Utah Prosthetic Insurance Fairness Law. At the close of the 2010, Utah became the 19th state to pass the Prosthetic Insurance Fairness Act.

Advocates, like Tami, are essential in the Amputee Coalition's grassroots efforts. According to Tami, no previous experience is necessary—only passion, perseverance, and patience. In 2010, nine states in addition to Utah introduced the Prosthetic & Orthotic Insurance Fairness bill. The Amputee Coalition trains Lead Amputee Advocates in key states and supports state-based initiatives to pass insurance fairness. The Amputee Coalition, working with the American Orthotic & Prosthetic Association and Hanger Orthopedic Group, is also working in the U.S. Congress to pass a federal Prosthetic & Orthotic Insurance Fairness law that will include self-insured companies which are not regulated by state laws.

*"I...am thankful that the Amputee Coalition continues to work in the remaining states and in Congress for insurance fairness. This is the right thing to do for those who have experienced limb loss."*

"Every morning I wake up and put on my prosthetic limb to tackle my daily life and I thank God I have insurance coverage," said Tami. "I also am thankful that the Amputee Coalition continues to work in the remaining states and in Congress for insurance fairness. This is the right thing to do for those who have experienced limb loss."

Tami Stanley worked tirelessly at the Utah State Capitol for a state law to assure insurance coverage for prosthetics.



## Overview

Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) that began in 1997, the Amputee Coalition developed and now manages the National Limb Loss Resource Center (NLLRC). The many patient education materials, information packets and resources available through the NLLRC are available at no cost to amputees and their families. Over the past 13 years, the NLLRC has served more than 100,000 information requests and provided online information to more than 4 million visitors to the online NLLRC.

## Outcomes

- Served more than 3,000 people affected by limb loss.
- Disseminated 4,500 special topic information packets.

## Highlights

- 80% of consumers report a positive impact from NLLRC.
- 90% satisfaction scores from consumers.
- 80% consumer approval for ease of use.

## Future Goals

- Develop an enhancement plan that expands resources and accessibility functions of information offered on the Amputee Coalition website.
- Develop an online healthcare provider directory.
- Provide new and improved web pages and integrated social media plans.

## Amputee Coalition National Limb Loss Resource Center

### At Your Request

“Thank you is usually the first response we get,” said Jim Meyers, Resource & Community Support Coordinator of the **Amputee Coalition National Limb Loss Resource Center (NLLRC)**. “We are serious about getting the right information and resources to the right people at the right time. We know our resource service can make a huge difference.”

And Jim is right. A 2010 survey of NLLRC consumers showed that the Amputee Coalition National Resource Center (NLLRC) has positive impact on consumers, family and friends of people who have experienced limb loss, who contact the Center. The NLLRC serves thousands of amputees and their families each year. This year more than 2275 requests for resources were fulfilled by the NLLRC.

The 2010 NLLRC survey also showed that consumers are satisfied with the materials received from the NLLRC, saying the materials addressed their questions. The NLLRC receives requests through email, the Amputee Coalition website and phone requests. The Center is staffed Monday through Friday 8 am to 5 pm eastern time with trained information specialists who offer a caring voice and timely resources to callers.

“We have packets of information because we consistently get requests on certain topics,” said Jim. “But each response is tuned to the individual who requested the information. Having real people in the Resource Center taking the requests allows us to put personal touches to each response.”

*“...each response is tuned to the individual who requested the information. Having real people in the Resource Center taking the requests allows us to put personal touches to each response.”*

The NLLRC provides connections to the Amputee Coalition National Peer Program and National Support Group Network which includes more than 1,200 civilian, military and Veteran Amputee Coalition certified peer visitors and over 250 registered support groups. The NLLRC extends its reach through the Amputee Coalition website and the online resource center. More than 400,000 unique visitors come to the Amputee Coalition website each year to find information and resources they need.

NLLRC materials are used by national partners such as the Veteran’s Administration Amputee System of Care and the Commission on Accreditation of Rehabilitation Facilities (CARF) as well as hundreds of care facilities across the country and abroad.



*"Thank you so much for your information. Your organization has been very helpful and I'm hoping to introduce more of my patients to your organization. I run the clinic for patients with amputations here at Loma Linda University."*

— Joan

*"Thank you so much for this information. My little son just turned 10 years old and battling cancer and now dealing with amputation is overwhelming. Thank you for your help and support. I would like to make sure Truman gets to attend the Amputee Coalition of America Youth Camp next summer, this would be so great for him."*

— Kimberly

*"Thank you. The information you provided is just what I need. We will go through the material together and at our first consultation with the surgeon ask appropriate questions about the surgery, prosthesis, rehabilitation, etc."*

— Elaine



## Overview

The Amputee Coalition's Paddy Rossbach Youth Camp's mission is to make a difference in the lives of children with limb loss and limb difference by increasing their self-confidence and self-esteem through a traditional and supportive summer camp experience. The camp is a 5-day traditional summer camp experience for children ages 10-17 who have lost arms and/or legs or who were born with limb differences. The camp offers challenging activities that builds campers' confidence regardless of skill level. A unique aspect of the program is that campers are not accompanied by their parents, which inspires campers to take on new challenges, be independent, test themselves and build new friendships in a supportive, caring environment.

## Outcomes

- 95% of campers identified at least one aspect of camp that helped to improve their feelings of independence.
- 96% of campers identified at least one aspect of camp that helped them feel more self-confident.
- 96% of campers will continue to participate in at least one physical activity after returning home from camp.
- 89% of campers will keep in touch with at least two campers from this year's camp.

## Future Goals

- Become the national model in summer camp programs for children with limb loss/limb difference.
- Support 100 campers at the 2011 Amputee Coalition Paddy Rossbach Youth Camp.
- Develop long-range strategies to expand the camp's reach.

## Amputee Coalition's Paddy Rossbach Youth Camp

### Camp—Home Away from Home

I thought I was a pretty well-adjusted kid despite the adversity of losing my leg to cancer at the age of nine. I am strong-minded and emotionally pretty tough, so I didn't think I needed to attend the **Amputee Coalition's Paddy Rossbach Youth Camp**. My mom made me go. Little did I know the experience would be absolutely instrumental in my life and to my self-confidence as an amputee.

My first experience as a camper changed me for the rest of my life. While holding my own athletically and socially in my community of friends and fellow students was important, I had been missing the self-acceptance of actually being different—and being comfortable with being different. July 2010, I became camp counselor at the Amputee Coalition Paddy Rossbach Youth Camp. We had 100 amputee campers from Florida to Alaska, even other countries. To my surprise, as a counselor I was even more impacted by the effect the camp has on the kids—and myself.

*"My first experience as a camper changed me for the rest of my life."*

Each camper is typically the only amputee in their community at home, which can be very isolating and lonely. The awkward impact of your amputation on other people who are uncomfortable with disabilities can be unfair and extremely hurtful, especially for kids. At camp, arms and legs are not an issue. As a counselor, I work with 15-17 year-old girls assigned to my cabin. I built relationships and strong bonds of trust with each of them, and they opened up to me about their feelings about their amputation, as well as the usual struggles of everyday teenage girl life: hair, makeup, boys, prom.

I have never ever in my life seen a group of kids with such vast differences in lifestyles and backgrounds be so supportive of each other during camp. We often say in our cabin, home is where the heart is and for four short days each summer camp is our home away from home.



**Click on  
the video**  
to learn more about  
**Amputee Coalition's  
Paddy Rossbach  
Youth Camp.**

Lacy Henderson found the Amputee Coalition's Paddy Rossbach Youth Camp to be "absolutely instrumental" to building self confidence as an amputee.



## Overview

The Amputee Coalition National Conference is the only national gathering in the United States of amputees, family and health care providers. The National Conference began in 1994 and has grown to more than 800 attendees, a robust expo hall, and an exciting compendium of educational sessions from pain management to rock climbing. The National Conference occurs every other year with the location moving around the country based on attendee interest and accessible hotel/conference space. The 2010 Conference was held in Irvine, CA and more than 800 amputees, families and professionals attended various programs, including an adaptive surfing program.

## Outcomes

- 800+ attendees
- Attendees feel more capable in overcoming environmental barriers.
- Most attendees learned something that will help them live a fuller life as an amputee.
- Most feel better able to make decisions regarding their healthcare.
- Most caregivers learn more caregiving skills at conference.
- Attendees have a more positive outlook concerning living with limb loss.
- Most say they will lead a healthier lifestyle.

## Future Goals

- Increase attendance to 1,000.
- Increase public recognition and brand awareness.
- Increase participation of local support groups.
- Increase volunteer involvement.

## Amputee Coalition National Conference Texas Whirlwind

It was a whirlwind—but the most life-changing whirlwind that I can imagine,” said Rev. Bill Simmons from Texas. I lost my left arm above the elbow in March and by August, I had joined the Dallas Amputee Network and headed to my first **Amputee Coalition National Conference** in Irvine, CA. Attending the National Conference was like getting a head start on the rest of my life. Losing a limb is a huge life change, but being able to go to one place and get the knowledge and skills necessary to live life as an upper extremity amputee made a world of difference. Being among so many people that share such a life-changing common bond is extra special. I learned many great things that will play an extremely valuable role for the rest of my life—AND I have made life-long friends who I expect to see at all the upcoming Amputee Coalition National Conferences which I won’t miss for the world.

*“Attending the National Conference was like getting a head start on the rest of my life.”*



Attending the Amputee Coalition annual conference was a life changing “whirlwind” experience for Rev. Bill Simmons.



**Click on  
the video**  
to learn more  
about the Amputee  
Coalition National  
Conference.

Attendees are learning by actively participating and trying out new equipment on display at the 2010 Annual Conference.



## Overview

Limb loss makes a huge impact on individuals and is a cost burden to the health care system. This year, the Amputee Coalition held the first Limb Loss Task Force Summit comprised of experts in limb loss—physicians, podiatrists, nurses, physical therapists, prosthetists, health behavior experts, and researchers from the private and public sectors, the military and the federal government. The Task Force developed a Four Point Action Plan that has become the roadmap to improving care for amputees and impacting limb loss prevention. The 2010 Limb Loss Task Force Summit was made possible through funding from the Centers for Disease Control and a grant from ev3, an endovascular company. The 2010 meeting was only the beginning.

## Outcomes

### Four Point Action Plan

1. Develop and Implement a Blueprint for Limb Loss Prevention.
2. Develop Care Guidelines for People Living with Limb Loss.
3. Develop a National Research Agenda on Limb Loss Prevention and Amputation Care.
4. Create and Demonstrate Model Systems of Care Ranging from Prevention through Amputee Rehabilitation and Community Integration that can be Emulated by Health Systems throughout the Country.

## Future Goals

- Convene Limb Loss Task Force Summit II in 2012.
- Develop a limb loss risk assessment tool.
- Cultivate relationships with like-minded organizations.

## Limb Loss Task Force *Building the Roadmap*

On average, 507 people lose a limb every day in the United States. And, this number is expected to almost double by 2050, unless a major public awareness campaign is launched and key prevention initiatives put in place, according to an expert task force convened by the Amputee Coalition in Washington D.C. on April 16-18, 2010. The **Limb Loss Task Force** was convened to develop a series of recommendations that will serve as the roadmap to limb loss prevention and improved care for amputees across the country.

“The current incidence numbers are alarming, and we need people to understand that limb loss can happen to them,” said Dr. Terry Sheehan, Amputee Coalition’s Medical Director and Board of Directors member. “Getting limb loss included as a consequence to smoking and obesity, just like stroke and heart disease, is key. Raising public awareness and getting this discussion included in care pathways by care providers for people with early onset diabetes and peripheral arterial disease is crucial.

*“Getting limb loss included as a consequence to smoking and obesity, just like stroke and heart disease, is key.”*

“Convening this Task Force is a step in the right direction,” continued Dr. Sheehan. “And we are confident the support of the task force combined with our organization’s execution of the four point plan, will provide a powerful impact in the fight against limb loss and the pursuit of improved amputee care.”

The Task Force reviewed in-depth facts and figures that demonstrate the urgency for a strategic approach to limb loss prevention and improved amputee care. The task force, consisted of experts in limb loss—physicians, podiatrists, nurses, physical therapists, prosthetists and researchers from the public sector, the military and the federal government.



# Key Metrics

## Impact Metrics

The Amputee Coalition 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 2010, the Amputee Coalition analyzed the effect of our various outreach initiatives and documented the following impact:

### Lives Benefited

Number of Amputee Coalition Certified Peer Visitors . . . . .	154
Number of Peer Visits Reported . . . . .	6,427
People Served Through Resource Center . . . . .	4,600
Web Site Visits . . . . .	497,132
Unique Web Site Visitors . . . . .	387,692
National Conference Attendance . . . . .	797
Support Groups . . . . .	250
Youth Campers . . . . .	100

### Community Outreach

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

National, Regional and Local Exhibits . . . . .	31
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### The People of the Amputee Coalition

Board Members . . . . .	12
Total Employees . . . . .	29
Medical Advisory Committee Members . . . . .	9
Volunteers . . . . .	833
Volunteer Hours . . . . .	13,277

## Resources

### Support and Revenues

Grants . . . . .	\$ 1,727,145
Sponsorships . . . . .	141,000
Contributions . . . . .	186,363
Publication advertising . . . . .	249,061
Memberships . . . . .	290,551
National conference . . . . .	250,343
Other . . . . .	42,833
Total support and revenues . . . . .	\$ 2,887,296

### Expenses

Program services	
National Limb Loss Center . . . . .	1,269,543
Advocacy . . . . .	254,176
Membership . . . . .	203,103
Publications . . . . .	145,879
Conference . . . . .	128,178
Youth programs . . . . .	111,011
Other program services . . . . .	19,438
Total program services . . . . .	\$ 2,131,328
Management and general . . . . .	490,126
Fundraising . . . . .	329,241
Total expenses . . . . .	2,950,695
Change in net assets . . . . .	(63,399)
Net assets at beginning of year . . . . .	712,309
Net assets at end of year . . . . .	\$ 648,940



# Thank you to our 2010 donors and supporters

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To reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention.

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