amputee coalition™
A donor-supported nonprofit

# Annual Report 2016

Compassionate Commitment

# LETTER FROM THE 2016 BOARD CHAIR

**Jack Richmond**
2016 Board Chair

Greetings,

In 2016, we continued to drive great progress and had great impact on the nearly 2 million people in the United States affected by limb loss and limb difference. I'm particularly proud of the following areas and the perspective that each and every contact matters.

## National Limb Loss Resource Center

To successfully achieve our mission to empower people, we start with education. Our National Limb Loss Resource Center is the only one of its kind. Available through phone or email, the specially trained team leads callers through a personal assessment, then provides the information and publications that best fit the individual.

## 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.

## Our Impact

In partnership with our sponsors, donors and volunteers we serve people living with limb loss and limb difference, their caregivers, clinicians, family and friends.

## Record-Breaking Events

It is exponentially difficult to achieve record-breaking numbers two years in a row, but we did it. Our National Conference in Greensboro, North Carolina, set a new bar for attendees with more than 1,000 people coming together to challenge themselves and each other.  We instituted a “living with my level of limb loss” series, added unique content like upper-limb and pediatric sessions and made sure we built in time to enjoy being together in a beautiful city.

## Meaningful Advocacy

We also built on our 2015 policy success by actively joining partnerships and coalitions with similar goals. Most important is ensuring access to appropriate, high-quality care, the kind of care that allows our community to live the life of their choosing.

## Peer Support

Turning to others for comfort and insight is instinctive, and we facilitate that action through our peer matching process, coupled with our peer support group calendar. These tools help us connect those who reach out with someone who had a similar experience.

Through it all, our volunteers, sponsors, members and supporters of all kinds make our work come alive. Because of the financial and sweat equity resources we benefit from, we are able to reach many more people than we could alone. I am incredibly grateful for their commitment and passion.

Jack D. Rich

Jack Richmond
2016 Board Chair

Our National Limb Loss Resource Center has thousands of conversations with people every year, covering topics from what to expect about limb loss to questions about housing, employment and family life.

Through our Peer Support program, we connect people with Coalition-trained certified peer visitors who can share their experiences and help provide support and insight. We also support over 400 support groups for more follow-up.

We provide education and build partnerships to help amplify the voices of people with limb loss, whether on Capitol Hill, in an insurance company’s office or in the community.

# Committed to Connection

## Empowering Through Education

Our programs spring from the benefits of peer-to-peer connection, education and effecting change through advocacy. To reach people new to limb loss as well as people who are well into their journey, we communicate directly through our staff, via digital and social channels, at events and through our advocates and volunteers. We reach tens of thousands of people every year, distributing more than 60,000 copies of *inMotion* magazine, teaching via interactive Webinars, mailing more than 5,000 copies of the *Your New Journey* packet and gathering more than 1,000 people at our National Conference.

The information we provide most often?

1. Our New Amputee Packet
2. Information about financial assistance for prosthetic limbs and medical equipment
3. Local resource options for housing and vehicle modification
4. Support groups and peer visits
5. Contact information for state organizations that address rights under the ADA and similar standards

Thinking of the future, we are laying a foundation with our Paddy Rossbach Youth Camp for children age 10-17 and Leadership Camp for adults age 18-19. We covered all costs (including travel), which meant 137 campers could focus on being the "normal" kid, enjoying new experiences and making life-long connections.

The numbers paint a picture of the many people we impact, but it is the individual responses that demonstrate the power of making connections with and for people living with limb loss and limb difference.

> *"To meet others that share your experiences and to learn from others that have walked the path before you is immeasurable."*
>
> ~Conference attendee

# The Top Limb Loss Resource

The National Limb Loss Resource Center is at the forefront of our outreach, responding to thousands of questions every year. Housed in our Knoxville, Tennessee offices, the highly trained team fields calls and emails from people with limb loss, family, friends, caregivers, clinicians and many more. Their answers range from a brief email to hour-long conversations, tailoring their response to the person and their request. The approach to every contact is the same: to thoughtfully assess the individual's needs and provide information that will help them live the life they choose.

> *"The Resource Center put me in immediate touch with existing amputees. There are no words to describe the benefit to know you are not alone and 'someone has been there, done that.'"*

~Amputee Coalition member

## IMPACT

**89.2%** of respondents said the overall impact of information/resources received was positive.

**87.6%** of respondents reported the materials they received were useful.

**86.8%** of respondents were satisfied overall with the materials they received.

## IMPACT

**88.4%** of individuals who received a peer visit were satisfied with their experience.

**69%** retention rate among hospital partners.

**7** new hospital and rehabilitation partners.

> *"Every day at work is rewarding … I work side-by-side with others, peer-to-peer. I offer strength, support, experience, lend a listening ear, but most of all, I get paid to spread hope."*

~Peer support volunteer

# Taking It Personally

## The Power of Peer Support

Our peer support programs build on a person's life experience, connecting them to a network of certified peer visitors, support groups and hospital partners across the country. Through our network, we offer support, strength and hope – moving closer to our goal that no one has to face limb loss or limb difference alone.

We are indebted to our thoroughly trained volunteer peer visitors. They go through our initial training and stay up to date with follow-up work and our regular certified peer visitor and support group meetings. (We even have special social media sites to keep them connected.) Many of our certified peer visitors are connected with hospitals or rehabilitation centers, which keeps them at the heart of recovery.

We know from the positive comments we receive that peer support is an important factor in helping people to move forward. We also know that prestigious organizations such as CMS, SAMSHA and the Institute of Medicine place a high value on peer-delivered services being offered through certified peer specialists. All of our referrals are personal. We take the time to review the individual's history, usually through a personal conversation. Then we match them as closely as possible with a peer visitor, paying extra attention to the areas that are most important to the person we are working with. These areas could include limb loss level, gender, age, and cause of limb loss.

Complementing individual connections are our peer support groups. More than a meeting, these people come together to share their stories and offer comfort and inspiration no matter when or how limb difference occurred.

# Speaking Out

## Making Advocacy Count

As a result of the Local Coverage Determination (LCD) that was proposed (and halted) in 2015, the Amputee Coalition introduced the Local Coverage Determination Clarification Act in 2016. The Act's purpose was to ensure that the people affected by changes in local coverage would have time and opportunity to comment and provide feedback on any proposed shifts in coverage – to shine a light on Medicare coverage decisions. The Act was introduced in both the House and the Senate with bipartisan support and provisions of the legislation were passed in the 21st Century Cures Act.

In 2016, the Coalition continued to lead the fight to ensure access to care by working with strategic partners to provide suggested language for both the Republican and Democratic party platforms before their respective conventions that highlighted the continued support for access to appropriate rehabilitative care. The Coalition continued to work with existing partnerships formed during its response to the LCD and serving as founding members of Partners for Better Care, steering committee member of the ITEM Coalition (Independence Through Enhancement of Medicare and Medicaid), and being actively engaged in the Coalition to Preserve Rehabilitation (CPR), the Disability and Research Rehabilitation Coalition (DRRC), the Consortium for Citizens with Disabilities (CCD), and the Transportation Security Administration Disability and Multicultural Coalition. These leadership platforms bring the limb loss community to the forefront, uniting with strategic partners to amplify our message.

During April, as part of Limb Loss Awareness Month, the Coalition hosted Hill Day, giving people a chance to come to Washington, D.C. and talk to their representatives about the issues impacting the limb loss community, the importance of access to rehabilitative care in Medicare and private insurance and the programs and resources that facilitate independent living.

Identifying issues of importance to the people the Coalition serves and finding effective ways to take action is critical to the future well-being of people living with limb loss and limb difference. There is no substitute for speaking up and speaking out!

# Making It Count

## Peer Support Network

**99** New Certified Peer Visitors

**362** Limb Loss Support Groups

**750** Active Certified Peer Visitors

**21** Hospital Partners

**349** Facility Members

## National Limb Loss Resource Center

**5,673** people served

**15,214** resources disseminated through center

Almost **90%** said overall impact was positive

## Advocacy

Founding member of Partners for Better Care

Partner with AOPA, O&P Alliance, Independence Through Enhancement of Medicare/Medicaid (ITEM) Coalition, Coalition to Preserve Rehab (CPR)

Disability Research and Rehabilitation Coalition (DRRC), Consortium for Citizens with Disabilities (CCD), National Health Council (NHC)

Introduction of the LCD Clarification Act in House and Senate

Introduced insurance fairness legislation in **4** states

## Reaching Out

**137** children with limb loss attended Youth Camp

**1,000+** attended National Conference in Greensboro, North Carolina

**269** attendees at Limb Loss Education Days

**110,000+** Facebook friends

**9,755** *Insurance Guides*
**15,679** *First Steps*
**5,041** *Your New Journey* packets mailed

# Financials

Being able to serve people living with limb loss and limb difference rests on solid financial health, which we achieve by following three principles.

1. We prioritize programs we believe will provide the support we promise in our mission, and then we assess them by asking participants what worked well for them.
2. We test new ways to serve and amplify the voice of the community, starting small and expanding if we are successful.
3. We are conservative with our expenses and long-term commitments to ensure that our core programs are always strong and able to deliver on our mission.

## Statement of Activities

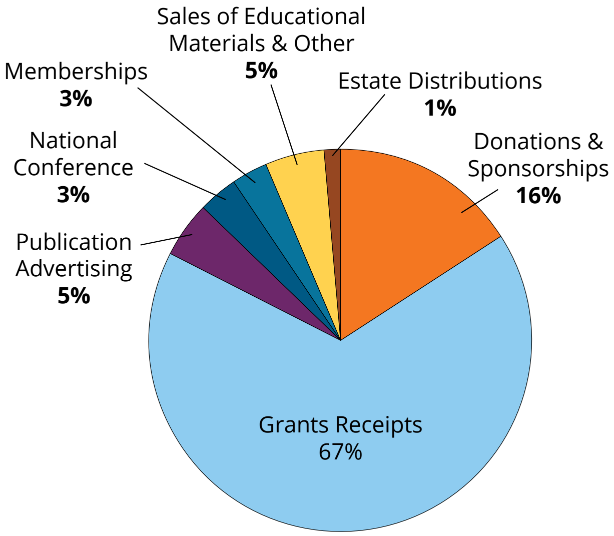
### Support and Other Revenue

| | |
|---|---|
| Donations & Sponsorships | $690,868 |
| Grants Receipts | 2,880,327 |
| Publication Advertising | 202,633 |
| Memberships | 141,649 |
| National Conference | 142,130 |
| Sales of Educational Material & Other | 215,171 |
| Estate distributions | 49,018 |
| **Total Support and Other Revenue** | **$4,321,796** |

### Expenses

| | |
|---|---|
| Program Services | $2,598,061 |
| Management & General | 700,304 |
| Fundraising | 229,334 |
| **Total Expenses** | **$3,527,699** |

## Support & Other Revenue



## Statement of Financial Position

### Assets

| | |
|---|---|
| Cash & Equivalents | $1,440,125 |
| Investments | 469,793 |
| Accounts Receivable | 11,840 |
| Contributions Receivable | 322,795 |
| Grants Receivable | 126,929 |
| Other Current Assets | 142,457 |
| Fixed Assets | 74,711 |
| **Total Assets** | **$2,588,650** |

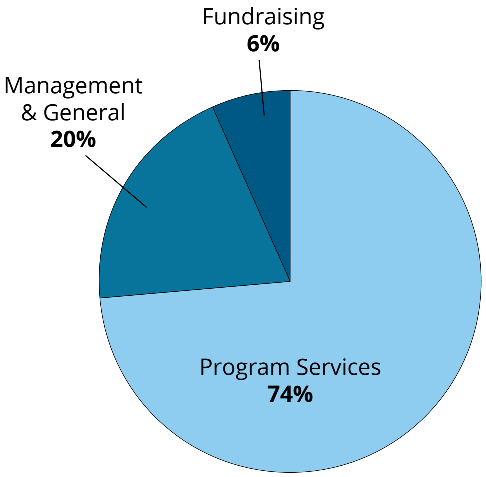
### Liabilities

| | |
|---|---|
| Accounts Payable & Accrued Liabilities | $215,421 |
| **Total Liabilities** | **$215,421** |

### Net Assets

| | |
|---|---|
| Unrestricted Net Assets | $1,479,753 |
| Temporarily Restricted Net Assets | 893,476 |
| **Total Net Assets** | **$2,373,229** |
| **Total Liabilities & Net Assets** | **$2,588,650** |

## Expenses



# Thank You to Our 2016 Donors

**Because of people like you, we can say YES to the people we serve.**

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Touro Rehabilitation Center

All 21 VA VISNs (Veterans Integrated Service Networks)

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## Strategic Partners

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American Association on Health and Disability (AAHD)
American Diabetes Association
American Orthotic and Prosthetic Association (AOPA)
Association of University Centers on Disability (AUCD)
Bader Consortium
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Challenged Athletes Foundation (CAF)
Coalition to Preserve Rehab (CPR)
College of American Pathologists
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Department of Labor (DOL)
Disability & Rehabilitation Research Coalition (DRRC)
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*In Memoriam:*
Dennis Fields, 2016 Board Member

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Thank you for believing in our mission
and making it a reality
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Learn more about making a contribution and getting involved in amplifying the limb loss community's needs.

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