




amputee  
coalition™

# The Amputee Coalition's National Limb Loss Resource Center

Meeting the Information and Resource Needs of the Limb Loss Community

**Disclaimer:**

**This project was supported, in part, by grant number 90LL0002-01-00, from the Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.**



# Our Mission

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



amputee  
coalition™

30<sup>th</sup>  
Anniversary

# Organizational Overview

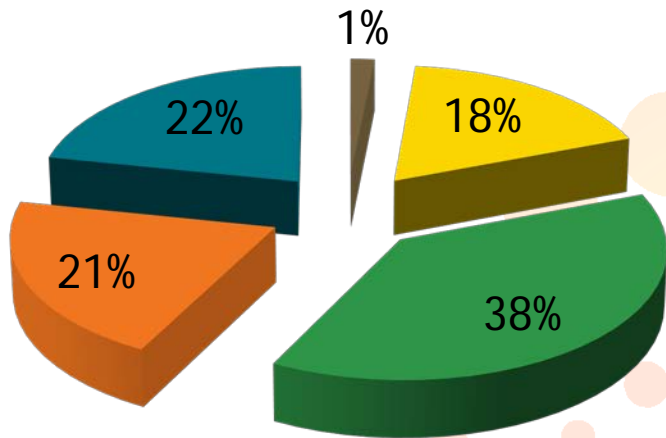
- The leading donor-supported, national non-profit organization serving the limb loss community
- 30<sup>th</sup> Anniversary
- Headquartered in Manassas, VA with a branch office in Knoxville, TN
- 19 staff members

# Organizational Reach

- More than 300 support groups in our network
- Over 1,000 Certified Peer Visitors across the country
- 65,000+ friends in database
- 100,000+ Facebook community
- 800,000+ Web site visitors

# Limb Loss Community

- 2.1 million persons with limb loss



■ Under 18  
■ 45 - 64  
■ 75+

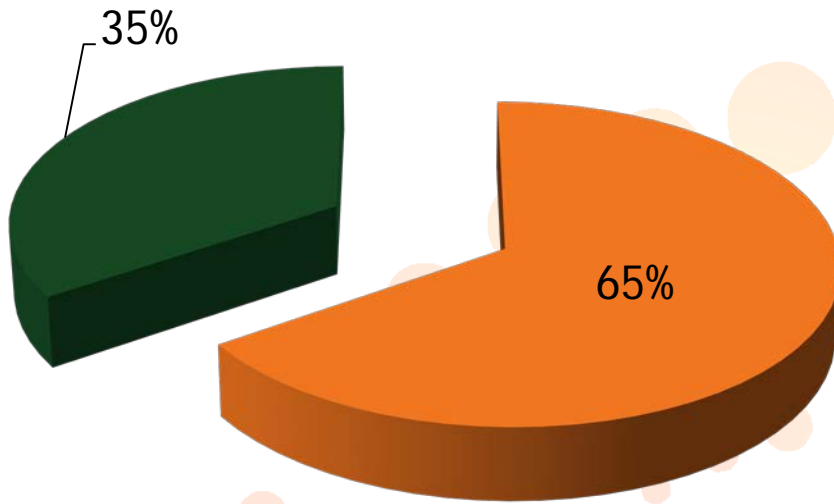
■ 18 - 44  
■ 65 - 74





# Amputation Levels

Level of Limb Loss



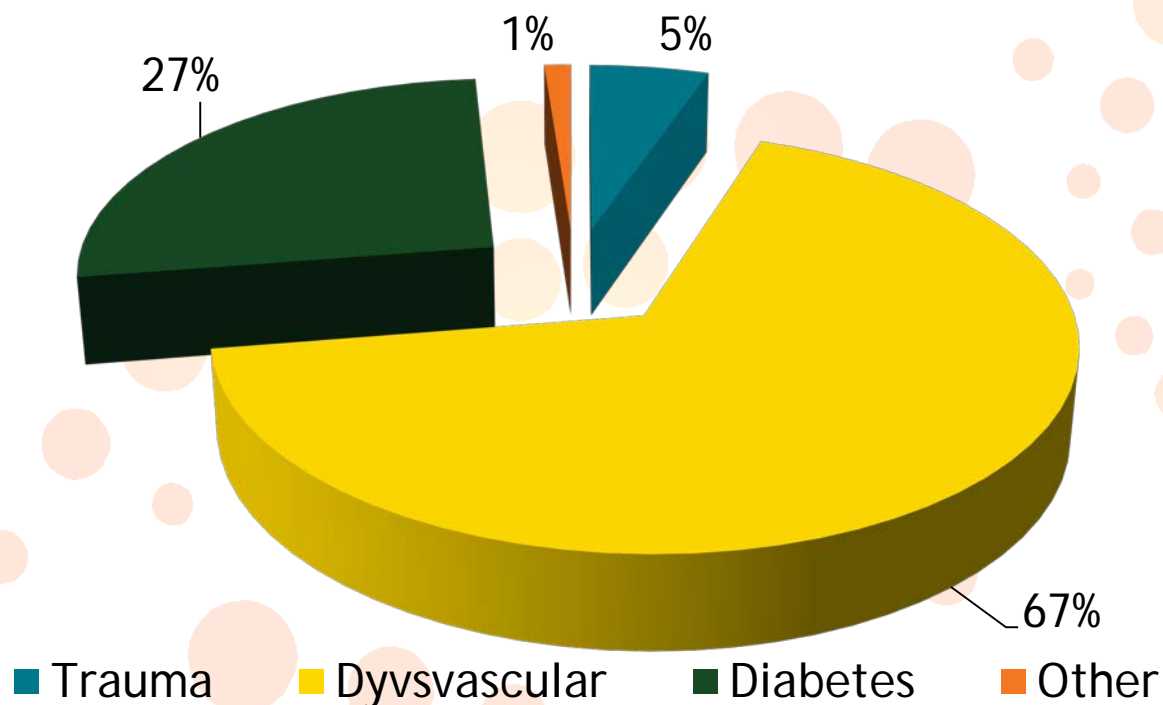
■ Lower Limb ■ Upper Limb



# Causes of Amputation

2012 - 131,510 amputations performed in US

(Source: Healthcare Cost and Utilization Project [HCUP] Nationwide Inpatient Sample [NIS], 2012.)





# Adapting to Limb Loss

- Variety of assistive technologies



# Living with Limb Loss

- Range of functional abilities
- Other health conditions/disabilities:
  - Diabetes
  - Depression
  - Traumatic Brain Injury
  - Post-Traumatic Stress



# Availability of Patient Education Materials

- Prior to Amputation
  - 53% - little to no information about prosthetics
  - 59% of no source of information about prosthetics

Source: Seaman, JP. 2010. Survey of Individuals Wearing Lower Limb Prostheses. Journal of Prosthetics and Orthotics. Vol 22. No. 4.

# Information Needs of PWLL

## Topics

- Questions
- Fears
- Concerns

## Delivery

- Method
- Content
- Other

## Approach

- How to deliver
- When to deliver
- How much



# Information Topics

- Wound Management
- Pain Experiences
- Phantom Limb Sensation
- Rehab Expectations
- Prosthetics/Assistive Technology
- Financial
- Support
- Recovery Process

# Delivering Information

## Age

- Hearing/vision loss, co-morbidities
- Younger generation

## Pain/Medication

- Impair ability to absorb information

## Emotions

- Fear, anxiety, shock
- Change perception of information

## Environment

- Distractions
- Friendly and supportive

## Education

- Avoid technical terms

# Patient Education Approaches

## Timing

- Pre-operative
- Post-operative

## Mode

- Verbal
- Written
- Video

## Amount

- Too much
- Too little



# Programs and Services

- Peer Support Network
- Self-management programs
- Educational Events
- Youth Camp
- Patient Education publications
- Information and Referral Center




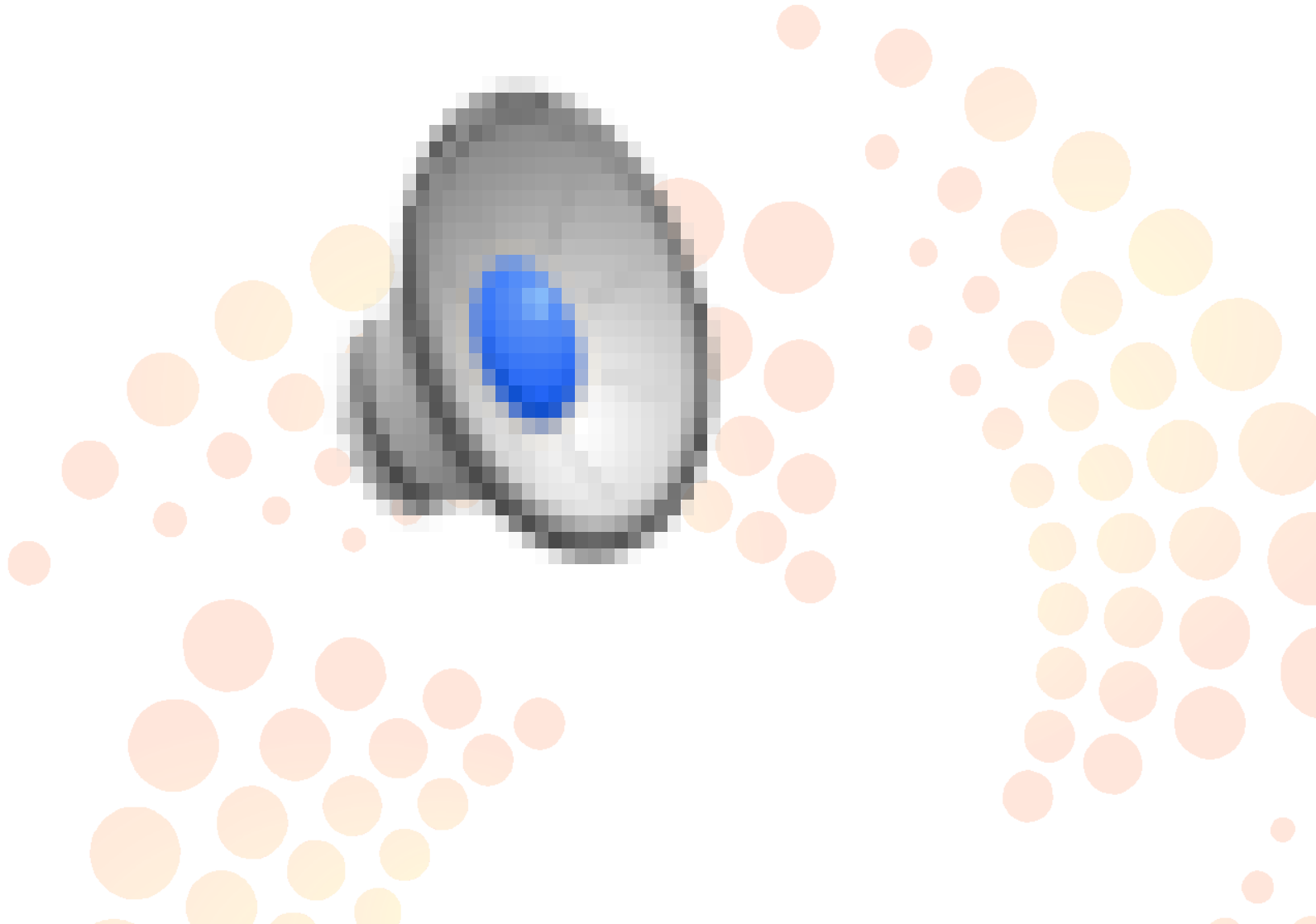
# Certified Peer Visitor Program

- First peer visitor training held in 1993
- Now over 1,000 certified peer visitors and growing!
- Extensive matching process
- Can request a peer visit online or by phone
- Non-biased and non-affiliated



# Youth Camp

- Free
  - Traditional summer camp
  - Ages 10 - 17
  - Clarksville, OH
  - ~130 campers
- 



# Limb Loss Resource Center

- Serves thousands of individuals each year
- Provide free educational resources
- Call Center
  - Monday-Friday 8:00am-5:00pm
  - Email, Web, and Phone Inquiries
- Website
  - “Library” of materials available
- Publications



# Sample Resources

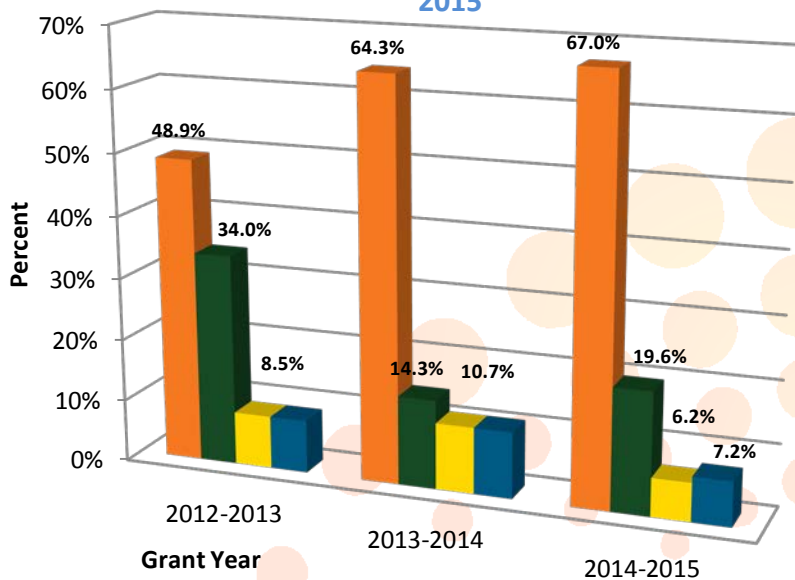
- Customized Information Packets
  - Specific to patient's needs
    - E.g., Phantom Pain, Wound Care, Shoes
- Local Resources
  - Home modifications



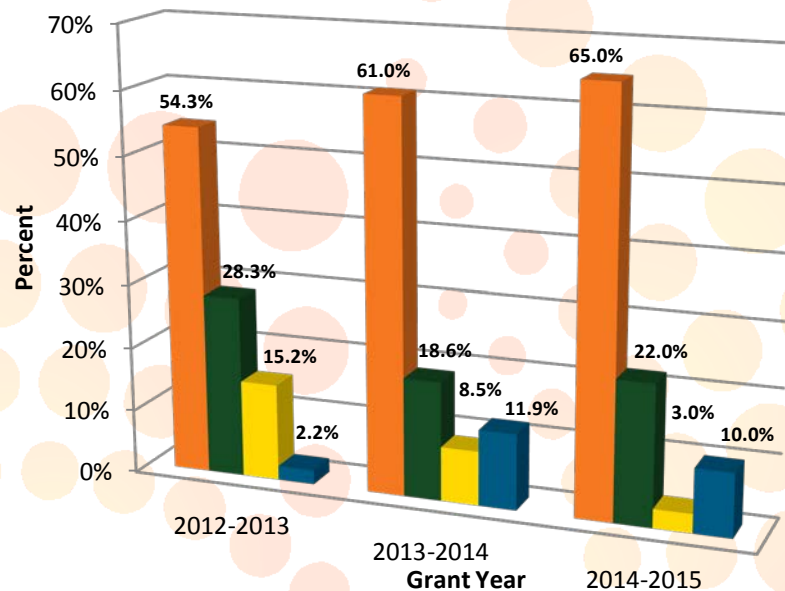


# Limb Loss Resource Center

Overall satisfaction with materials received, 2012-2015



Usefulness of materials received, 2012-2015



■ Very satisfied 
 ■ Somewhat satisfied 
 ■ Somewhat not satisfied 
 ■ Not satisfied 
 ■ Very useful 
 ■ Somewhat useful 
 ■ Somewhat not useful 
 ■ Not at all useful

# Publications

- InMotion
- First Step/Premier Paso
- Insurance Coverage and Reimbursement Guide
- Brochure Series
  - First Step
  - Pain Management

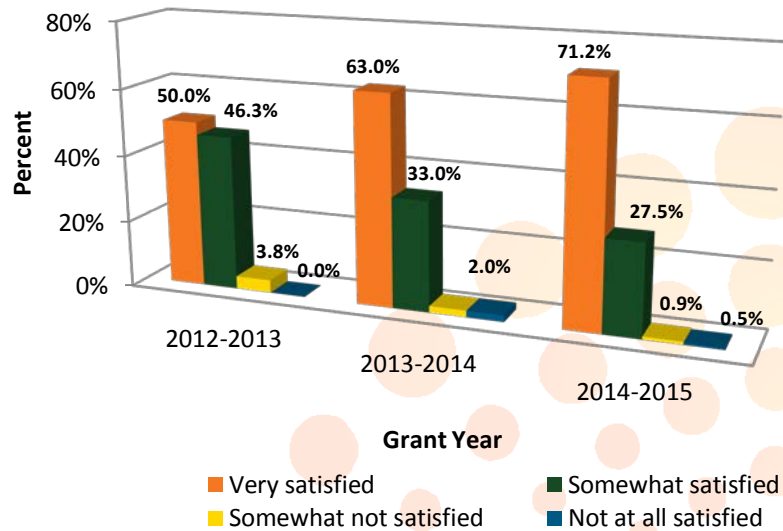


# Benefits of Publications

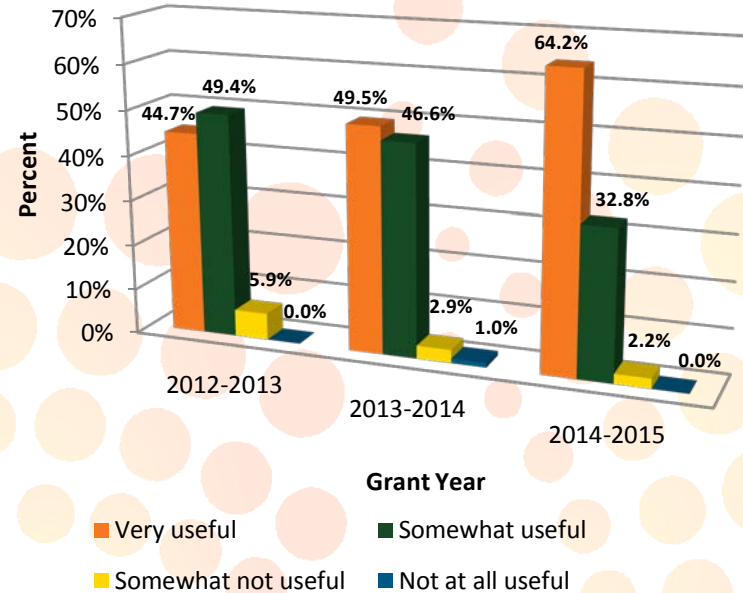
- Non-biased and patient centered approach
- Reviewed by clinicians and consumers
- Free

# Benefits of inMotion

Overall satisfaction with content of *inMotion*, 2012-2015

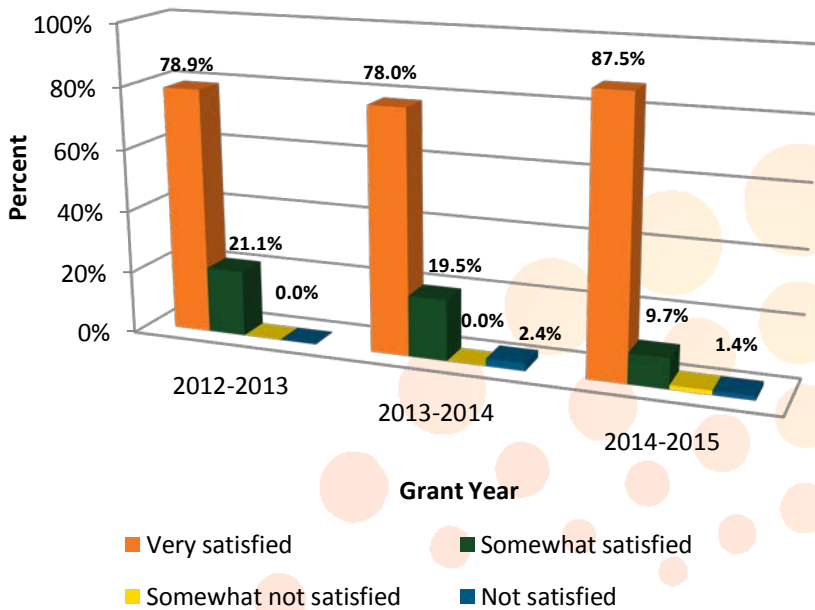


Usefulness of *inMotion* articles, 2012-2015

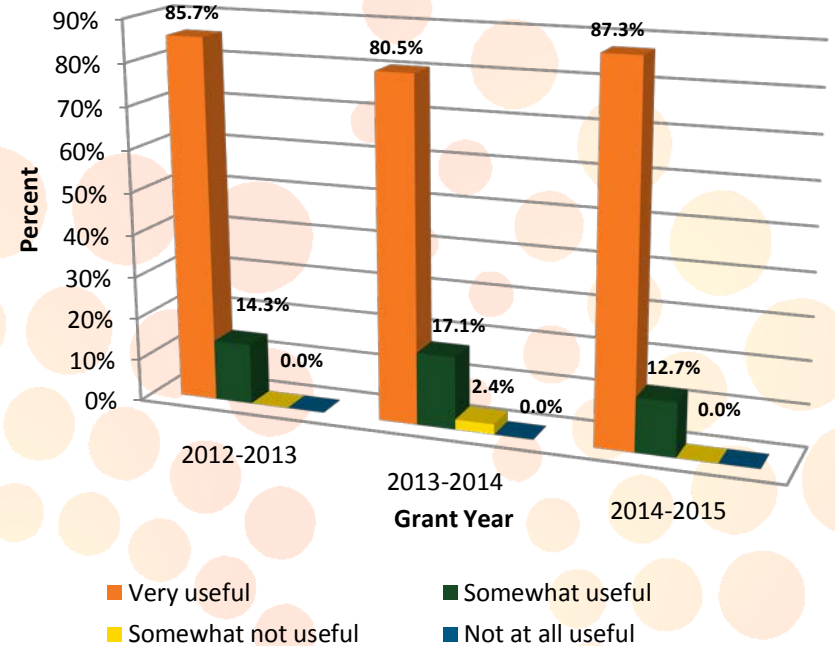


# Benefits of First Step

Overall satisfaction with information in *First Step*, 2012-2015

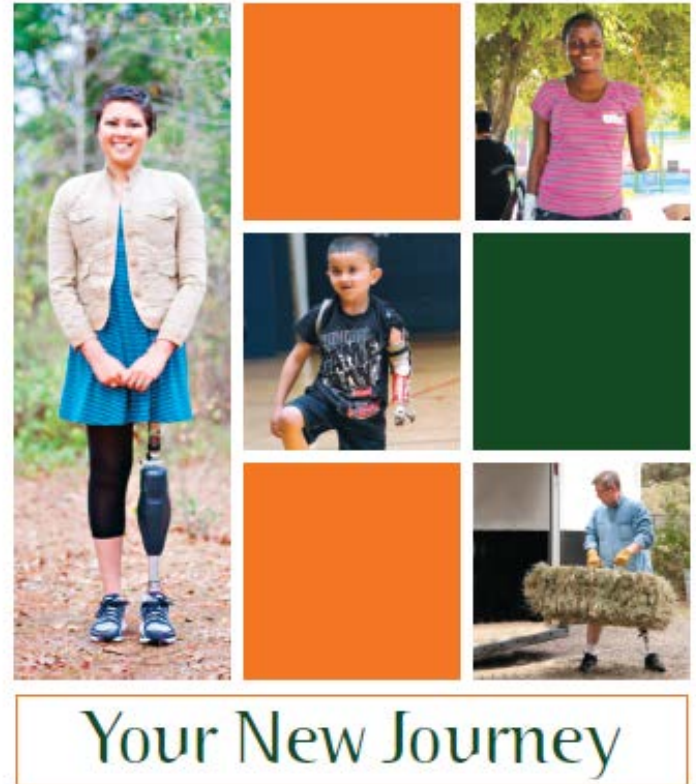


Usefulness of information in *First Step*, 2012-2015



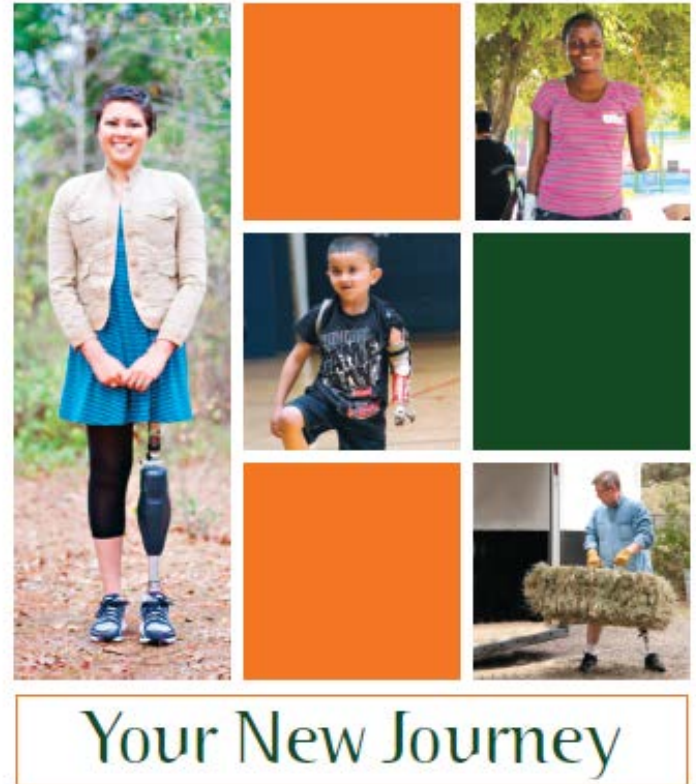
# Your New Journey Folder

- Evidenced-based
  - Information New Amputees need
  - Consumer and Clinician Reviewed
  - Not Overwhelming
- Available in Spanish



# Your New Journey Packet

- Folder
- First Step
- *inMotion*
- Amputation specific
- Brochures





# Patient Education Booklet

- Amputation/Topic specific resource
- Undergoing complete redesign
- Will be available 2016
  - Below Knee
  - Above Knee
  - Upper Limb
  - Hemipelvectomy/Hip Disarticulation
  - Caregiver
  - Pediatric Population





amputee  
coalition™

# Amputee Coalition Resource Center

The "Gateway" of the Amputee Coalition

# Who We Are/What We Do

- We serve the limb loss community, their families, their friends, caregivers, hospitals, rehabilitation centers, social service workers and the public as a whole.
- Anyone is welcome to contact the Resource Center for assistance.
- Our resources and materials are provided free of charge to individuals.

# Contact us

- Inquiries come into the Resource Center in a variety of ways.
- Via our toll-free number 1-888-267-5669
- Via our website [www.amputee-coalition.org](http://www.amputee-coalition.org)
- Via the postal mail and the occasional drop-by at either of our offices.
- Office hours are 8am-5pm (EST Mon-Fri).

# Who Contacts Us?

- Anyone is welcome to contact us.
- We receive inquiries, questions and comments from all 50 states as well as internationally.
- Limited support for international requests.

# By The Numbers

- Each inquiry or question the Resource Center receives becomes a case.
- Each case is researched, fulfilled and documented in our database.
- In 2015, we opened 4,361 cases (an average of 365 a month), and served 6,005 individuals.
- So far in 2016 we are averaging 460 cases a month, serving 491 individuals per month.

# Same, but different

- The Resource Center shares some similarities with 211 centers and CIL's.
- We field calls from the public, but we are not a traditional "call center".
- Small staff (3), no call queue system, not on the phone constantly (usually).
- Majority of our time is spent researching cases.



# However....

- When someone calls, we stop everything to focus on the caller and their needs.
- Calls can be as brief or as lengthy as the caller's need dictate.
- Shortest call (30 seconds) Longest 1 hour, 45 minutes.

# Other differences

- Create resources
  - First Step
  - Your New Journey
  - In Motion magazine
  - Insurance/Reimbursement Guide
  - Amputation Level Specific Information

# Working with you

- We refer our clients everyday to CIL's, 211 centers and other specialized information centers.
- Our clients very often are looking for local and specific resources.
- As we are a national organization, we rely heavily on you to connect our clients to programs and services in their community.

# Common questions

- Two overriding popular questions
- New Amputee Information
- Funding resources

# New Amputee Information

- Amputation may have been very recent.
- “I’m not even sure why I’m calling.”
- “Where do I go from here?”
- Truly a new journey
- Finding us via a google search.

# Funding

- Assistance with the co-pay of a prosthetic device.
- Can and do cost in the thousands of dollars.
- Other funding requests, home and vehicle modification.
- Help with social services and everyday bills.

# “Difficult calls”

- We have our share of people who are less than pleased with our services and/or organization.
- Belligerent, angry at the world.
- Difficult calls can take other forms.....

# What do we say?

- Victim of an automobile or motorcycle accident. They are at the hospital now. No memory of the accident and they will soon come out from anesthesia. They had a below knee amputation. How are we going to tell them? What do we say?



# What do I do now?

- A person who has worked for 40 years in the same job has lost her leg due to complications due to diabetes. She is unable to return to work. How can she pay her mortgage? What does she do now?

# What about Grandpa?

- A parent calls and ask how to tell their five year old son or daughter that Grandpa no longer has his arm?

# Now what?

- A man had both legs removed due to a vascular condition. He tells us he was sent home with a wheelchair and our phone number. His nearest family member is 200 miles away. Now what?

# Not uncommon, but still unique

- Over 2 million people live with limb loss.
- More than 28 million people are at risk.
- 185,000 amputations a year in the U.S.
- More than 500 a day.

# Numbers don't matter

- Incredibly personal and life-changing for the individual.
- No right answer, no time frames on recovery or rehabilitation.
- Courage

# “Those calls”

- ‘So, how long do I have to live?’”
- What would Benjamin Franklin do ?”
- Medical/Legal Advice

# Words matter

- What do I call you?
- Disabled or no?
- Courage (reprise)

# Find us

- 1-888-267-5669
- [amputee-coalition.org](http://amputee-coalition.org)
- Take a card



Thank you!

