

FALL 2025

Amputee-Coalition.org

*in*Motion

LIVING WELL WITH LIMB LOSS AND LIMB DIFFERENCE

THE ROAD TO 40:

Nearly Four Decades of IMPACT
- And What Comes Next



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FALL HEALTH & WELLNESS

STAYING STRONG THIS SEASON

As the seasons change, so do the needs of your body and mind. For individuals who have limb loss or limb difference, fall is the perfect time to focus on proactive health and wellness. From keeping skin healthy in cooler, drier weather to getting active safely and supporting emotional well-being, these practical tips can help you stay balanced, resilient, and ready to enjoy all that autumn has to offer.

1. Prioritize skin and limb care to prevent infections:

- Inspect your residual limb(s) regularly for any signs of irritation, redness, blisters, or ulcers.
- Keep skin clean and moisturized, especially in cooler, drier weather to prevent cracking.
- Use breathable socks and liners with prosthetic and orthotic devices to reduce moisture buildup and friction.
- If you have diabetes, maintain blood sugar levels and seek immediate care for any wounds.

2. Stay active safely with adaptive movement:

- Engage in low-impact activities such as swimming, walking, rolling, and yoga to maintain healthy circulation and mobility.
- Use assistive devices such as walking sticks, crutches, or wheelchairs to prevent falls and preserve energy.
- Work with a physical therapist, occupational therapist, and/or trainer at a local gym to develop a fall-prevention plan and strengthen your balance and core muscles.



3. Support mental and emotional wellness:

- Build a daily routine that includes meaningful goals and hobbies.
- Connect with **peer support** to share experiences and reduce isolation. Amputee Coalition offers Certified Peer Visitors, virtual support groups, and has a nationwide Support Group Network for in-person connections to choose from.
- Practice mindfulness and meditation to manage seasonal mood changes and stress.

A PUBLICATION OF THE DETAILS

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Amputee Coalition
25 Massachusetts Ave NW, Suite 650
Washington, DC, 20001

865-524-8772; 888-267-5669
Fax: 865-525-7917; TTY: 865-525-4512
Email: communications@amputee-coalition.org
Website: amputee-coalition.org
AC Connect: community.amputee-coalition.org

Interim President & CEO: William "Bill" Perno
Director of Communications & Partnerships:
Shree Thaker

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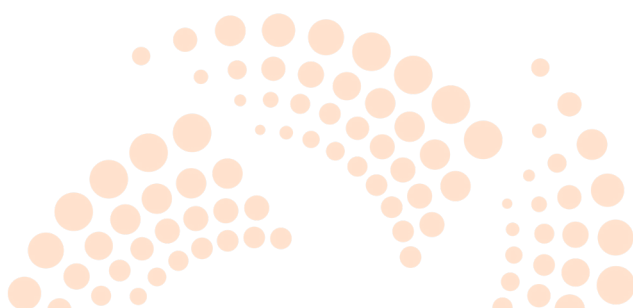
DISCOVER A RESEARCH OPPORTUNITY THAT'S RIGHT FOR YOU

Interested in participating in a research study? Visit the **Volunteer Research Opportunities webpage** at [Amputee-Coalition.org/volunteer-research-opportunities](https://amputee-coalition.org/volunteer-research-opportunities) for the most up-to-date listings. Your participation helps drive research forward and includes the limb loss and limb difference experience in scientific exploration- thank you for considering being part of these important studies.

A few current opportunities include:

- Upper Limb Prosthesis Use and Performance Survey
- Measuring Mobility Outcomes after Lower Extremity Amputation with Smartphone Data
- Evaluation of Powered Prosthesis for use with Transfemoral Osseointegration Recipients
- Experiencing and Coping with Phantom Limb Pain in the Early Postoperative Period Following Amputation
- Fatigue, Diabetes, and Falls by People with Below-Knee Amputations
- Understanding How Powered Componentry Impacts Transfemoral Amputee Gait
- Translating Outcomes that Matter Most to Individuals Living with Orthotics and Prosthetics to Shared Decision-Making in the Practice Setting
- Regenerative Peripheral Nerve Interfaces to Treat Painful Digit and Hand Neuromas After Amputation: A Prospective Observational Trial
- Understanding and Analyzing User-Prosthesis Interaction for Designing a Controller for Powered Lower-Limb Prostheses
- Controlling Locomotion over Continuously Varying Activities for Agile Powered Prosthetic Legs
- Analysis of Movement Quality with Transfemoral Osseo-integrated Prostheses
- Feasibility of Sensory Feedback for Lower Limb Amputees
- Evaluating the Impact of Prosthetic Device Features on the Experience of Prosthesis Use
- Psilocybin-Assisted Therapy for Phantom Limb Pain
- Virtual Reality Treatment of Phantom Leg Pain
- Remote tDCS and Somatosensory Training for the Treatment of Phantom Limb Pain

LEARN MORE



THE ROAD TO 40: A CELEBRATION OF CONNECTION, STRENGTH, AND THE JOURNEY AHEAD

For nearly four decades, the Amputee Coalition has been building bridges—connecting people who have limb loss or limb difference, their families, and caregivers to the resources, education, and support that make all the difference. As we approach our 40th anniversary in 2026, we're reflecting on how far we've come and where we're headed next: Las Vegas for ACNC26, our biggest celebration yet!

JOIN US FOR ACNC26: THE 40TH ANNIVERSARY CELEBRATION IN LAS VEGAS

Mark your calendars for January 11–15, 2026, as the Amputee Coalition brings the energy, innovation, and heart of our community to Westgate Las Vegas.

Hear from keynote speakers, interactive cutting-edge exhibits, and enjoy sessions designed to empower every member of the limb loss and limb difference community. From clinics designed to meet the various needs of people who have disabilities to Certified Peer Visitor training and both educational and wellness-oriented sessions, ACNC26 will be a can't-miss experience that honors our past and paves the way for the future.

WHERE TO STAY: WESTGATE LAS VEGAS

We've partnered with **Wheel the World**, a travel company that specializes in accessible experiences, to make booking your stay seamless. Reserve your room through our official room block to secure special conference rates.

If you plan to extend your stay outside of the conference dates, please note that these additional nights must be booked separately with the hotel.

WHAT YOU'LL NEED BEFORE YOU ARRIVE

To make the most of your trip, be sure to:

- Purchase your Conference Registration Ticket
- Book your hotel room via Wheel the World to access the official room block.
- Book your flights into Las Vegas (LAS)—arrive by Monday, January 12, and plan to depart no earlier than 7:00 PM on Thursday, January 15, to enjoy all programming.

ACCESSIBILITY AND MOBILITY SUPPORT

If you need a scooter or wheelchair during your stay, you can reserve one in advance through Scootaround:

- Visit: **Scootaround – Amputee Coalition 40th Anniversary**
- Under “Delivery Location,” select **Westgate Las Vegas Resort & Casino**
- Select your rental dates (January 11–16, 2026) and times, then proceed to checkout securely.

For **accessible transportation**, those who qualify for Paratransit in their home state can request “Visitor Status” with the **Southern Nevada Paratransit Program** by calling 702.228.4800 and asking for the **Certification Office** (open Monday – Thursday, 8 AM–4 PM local time).

Please note: the monorail does not connect the airport to the Westgate Resort and Casino. We recommend using paratransit; otherwise, taxis and rideshares will be required for transportation to Westgate.

Meet the Voices Taking the Mainstage at ACNC26

We're thrilled to welcome an extraordinary lineup of speakers who will bring energy, humor, and heart to the stage in Las Vegas.

- **Dr. James Dixon** - Tuesday Mainstage Program: Welcome to the Conference
- **Katy Sullivan** - Wednesday Mainstage Program: Actress. Athlete. Advocate.
- **Bill Zabelny** - Thursday Mainstage Program: Hall of Famer and Las Vegas Local
- Meet Your Host - **Michael Beers** - Comedian and Community Advocate



Together, these dynamic voices promise to make ACNC26 a celebration unlike any other—one filled with laughter, learning, and unforgettable memories.

MILESTONES THAT BUILT A MOVEMENT

Road to 40: Building a Stronger Community Since 1986

For nearly four decades, the Amputee Coalition has grown from a grassroots vision into a national force for connection, advocacy, and empowerment. Here are the milestones that brought us here:

• 1986 – HUMBLE BEGINNINGS

Founded by a small group of leaders determined to create a support group network for amputees.

• 1991 – CERTIFIED PEER VISITOR PROGRAM

Trained individuals began providing hope and guidance, sparking a nationwide peer support movement.

• 1997 – NATIONAL LIMB LOSS RESOURCE CENTER

Established with CDC support, now thriving with ACL funding as the trusted hub for programs.

• 2000 - YOUTH CAMP

Began as the initial Youth Initiative dedicated to youth and held in conjunction with the annual Conference.

• 2003 – NATIONAL CONFERENCE

Launched as the premier annual gathering for learning, networking, and community.

• 2010 – NATIONAL LIMB LOSS AND LIMB DIFFERENCE AWARENESS MONTH

April is officially recognized to celebrate strength and raise awareness worldwide.

• 2012 – EDUCATION DAYS

Local programs launched to bring learning and resources directly into communities.

• 2024 – VOICES AMPLIFIED

Innovated and revamped the Lead Advocate Certification Training and became the backbone for So Every BODY Can Move

• 2026 – 40 YEARS OF STRENGTH

Celebrating four decades of connection and expanding peer support to over 350 support groups and more than 1,000 Certified Peer Visitors.

JOIN US AS WE MAKE HISTORY IN LAS VEGAS!

WITH OUR LARGEST EVER IN-PERSON CPV TRAINING



This January, before the Amputee Coalition National Conference officially gets started, we're doing something BIG: training **150 new Certified Peer Visitors (CPVs)** all in one place. And we want you there!

WHY CPV TRAINING?

Being a Certified Peer Visitor means being there for others in the limb loss and limb difference community. It's about connection, listening, and sharing lived experience in a way only peers can.

Through this one-day, interactive training, you'll learn the skills and build the confidence to support others—whether that's in a hospital, at a community event, or online.

EVENT DETAILS

Certified Peer Visitor (CPV) Training

Pre-Conference Event | Amputee Coalition National Conference

Las Vegas, NV

Monday, January 12, 2026

8:00 AM – 4:00 PM MST

Breakfast and lunch are included!

WHO CAN JOIN?

People with lived experience of limb loss or limb difference (12+ months post-surgery)
Family members or caregivers supporting someone in the community

WHAT YOU'LL GAIN

- Practical skills for peer-to-peer support.
- Confidence to connect with others in real-life settings.
- Knowledge of Amputee Coalition resources.
- A place in history as one of the largest CPV training groups ever!
- A certificate of successful training completion.

READY TO MAKE HISTORY?

Be part of this record-breaking training in Las Vegas.

150 new CPVs. One unforgettable day. Let's make it happen—together.

Reserve Your Spot Today By:

Complete the CPV Training Application:



NOMINATE A VOLUNTEER WHO MADE AN IMPACT ON YOU!

**BEFORE WE GET STARTED... LET'S CELEBRATE THE
HEART OF THE AMPUTEE COALITION!**



At the Amputee Coalition, our volunteers are the heart of everything we do. They're the ones making calls, showing up for Certified Peer Visitor (CPV) meetings, running support groups, sharing their knowledge, and being alongside others during some of life's biggest transitions. Quite simply—our community is stronger because of them.

That's why each year we honor these incredible individuals through our **Values in Action Awards**. Inspired by the values our Board and staff live by, these awards recognize volunteers who put those values into practice every single day:

- **Compassion** – showing care and empathy.
- **Innovation** – bringing forward fresh ideas.
- **Service** – giving time and energy to help others.
- **Teamwork** – working together to get things done.

VOLUNTEER APPRECIATION AWARD

Each year at the **Amputee Coalition National Conference**, we take time to celebrate those whose actions reflect these values. It's our way of saying thank you for their dedication to the limb loss and limb difference community.

WHO CAN BE NOMINATED?

- Community members who have limb loss or limb difference.
- Caregivers.
- Anyone who provides meaningful support.

HOW TO NOMINATE

Think of someone whose actions truly reflect these values. Then, **complete the nomination form** to share their story and impact. Your nomination helps us spotlight the people who keep our mission moving forward. How to Nominate" as last sentence: Nominations will be accepted through Sunday, November 16th, 11:59pm ET.

RECOGNITION & CELEBRATION

Honorees will be celebrated at the National Conference, and their stories will be shared with our community nationwide.

Submit your nomination today—and help us celebrate the volunteers who are the true heart of the Amputee Coalition.





TRAVEL MADE EASY WITH **WHEEL THE WORLD**

Book with Confidence. Stay with Community. Experience ACNC26 Without Barriers.

We're proud to announce our expanded partnership with **Wheel the World** to ensure your hotel booking experience for the Amputee Coalition 40th Anniversary National Conference is smooth, accessible, and worry-free.

Wheel the World is a trusted travel company that makes it easy for people who have disabilities to plan trips. Their platform provides verified accessibility details for hotels, so you know exactly what to expect before you arrive.

For **ACNC26**, taking place **January 13–15, 2026**, Wheel the World is managing all hotel reservations—offering exclusive rates, verified rooms, and the convenience of staying right where the action is at the **Westgate Las Vegas Resort & Casino**.

WHY BOOK THROUGH WHEEL THE WORLD?

Special event pricing just for ACNC26 attendees

Stay where the conference is held—no commuting necessary

Be part of the community—connect and unwind with attendees all under one roof

Accessible rooms are limited, so we encourage booking early!

PLAN YOUR **ACNC26 VEGAS** ADVENTURE TODAY

RESERVE YOUR SPOT TODAY!



REGISTER TODAY

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BOOK YOUR ROOM

Wheeltheworld.com/campaign/amputee-coalition



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40YEARS.AMPUTEE-COALITION.ORG

RELIVING THE MOMENTS THAT MOVE US

A LOOK BACK AT CONFERENCE HIGHLIGHTS

Every Amputee Coalition National Conference is filled with moments that stick with us long after the closing session — the powerful keynotes that spark new ways of thinking, the breakout workshops where real skills are shared, and the conversations in hallways that blossom into lifelong friendships.

As we count down to **ACNC26 in Las Vegas**, we're taking a look back at some of the most memorable sessions and experiences from our last gathering. These highlights remind us not only of the progress we've made together but also of the energy and connection that makes our community so special. From thought-provoking speakers who challenged us to step outside our comfort zones, to interactive learning that equipped us with tools for daily life, to advocacy training that fueled the So Every BODY Can Move movement, the last conference was a celebration of community vibrance and possibility. And it was just the beginning.

In the pages ahead, you'll find recaps of sessions that informed and energized attendees. Whether it was diving into adaptive recreation, exploring advances in prosthetic technology, tackling healthcare access, or discovering new ways to share our stories, these sessions represent the best of what happens when we come together.



As you relive these highlights, we hope you'll also feel the anticipation building for what's next. Because if the last conference showed us anything, it's that when our community gathers, we don't just learn and connect — we create momentum for change.

HERE'S A GLIMPSE AT JUST A FEW OF THE HIGHLIGHTS YOU'LL FIND IN THIS ISSUE:

- **How Microsoft's Adaptive Tools Enhance Gaming and Productivity for All**
- **Beyond the Pain: Navigating CRPS and the Reality of Amputation**
- **Scleroderma and Raynaud's: Shedding Light on Their Overlap and Navigating the Path to Prosthetic Device Possibilities**
- **The Road to Recovery: The Untold Story Behind the Film Driving Mrs. M**
- **Osseointegration: A New Era in Bone-Anchored Prostheses and Patient Mobility**

Get ready. The Road to 40 is leading us to Las Vegas, and ACNC26 promises to be our most unforgettable celebration yet.

FROM ENHANCED GAMING TO PRODUCTIVITY: MICROSOFT'S ADAPTIVE TOOLS TOOK CENTER STAGE AT ACNC24

In a world where innovation is moving at lightning speed, **accessibility should never be an afterthought**—and Microsoft is leading the way by putting this at the heart of its technology. With a growing portfolio of adaptive tools and devices, Microsoft is reshaping the landscape for people who have disabilities by removing physical barriers to productivity and play. From the workplace to the virtual battlefield, their tools are **empowering users to connect, create, and compete—on their own terms.**

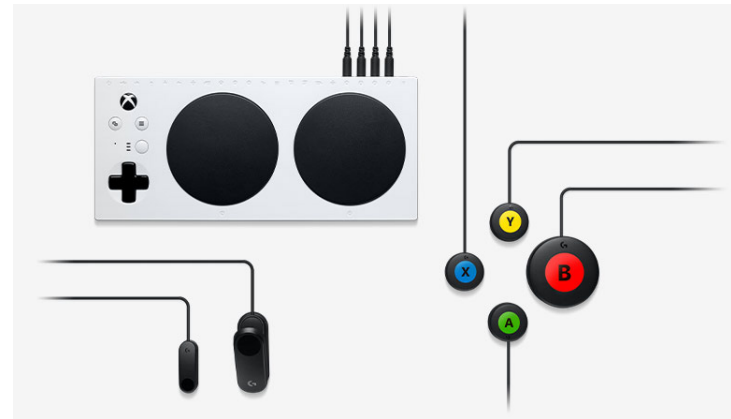
A COMMITMENT TO INCLUSIVE DESIGN

Microsoft's journey isn't new. It's built into the DNA of their mission: "to empower every person and every organization on the planet to achieve more." What sets Microsoft apart is its dedication to **all-embracing design principles**, involving people who have disabilities directly in the product development process to ensure real-world functionality. **The result? Tools that work better for everyone.**

GAMING WITHOUT LIMITS: THE XBOX ADAPTIVE CONTROLLER

A Game Changer in Every Sense

One of Microsoft's most celebrated innovations is the Xbox Adaptive Controller (XAC). Developed in collaboration with organizations like AbleGamers, SpecialEffect, and Warfighter Engaged, this revolutionary controller redefines who gets to be a gamer.



With two large programmable buttons, 19 3.5mm ports, and USB inputs that support a wide range of switches, joysticks, and mounts, the XAC is **infinitely customizable**. Whether a player uses their feet, head, or even their voice, the controller adapts to them—not the other way around.

Real Impact for Real People

Gamers who previously struggled—or were unable—to play now have access to immersive experiences and online communities. For many, this goes beyond recreation; it's about **belonging, expression, and joy.**

TOOLS THAT BOOST EVERYDAY PRODUCTIVITY

Microsoft's commitment doesn't stop at gaming. It extends into every corner of their software ecosystem, particularly with Microsoft® Surface, Windows 11, Microsoft 365, and adaptive accessories designed to enable seamless



computing. Some of those features include:

Windows Accessibility Features

Windows 11 includes built-in features like:

- **Voice Access:** Control your PC using just your voice.
- **Live Captions:** Real-time captioning of any audio content.
- **Magnifier & Color Filters:** For users with low vision or color blindness.
- **Narrator:** A screen reader that helps users navigate without needing to see the screen.

Microsoft 365: Tools That Work for You

In Microsoft Word, PowerPoint, Outlook, and more, users benefit from features like:

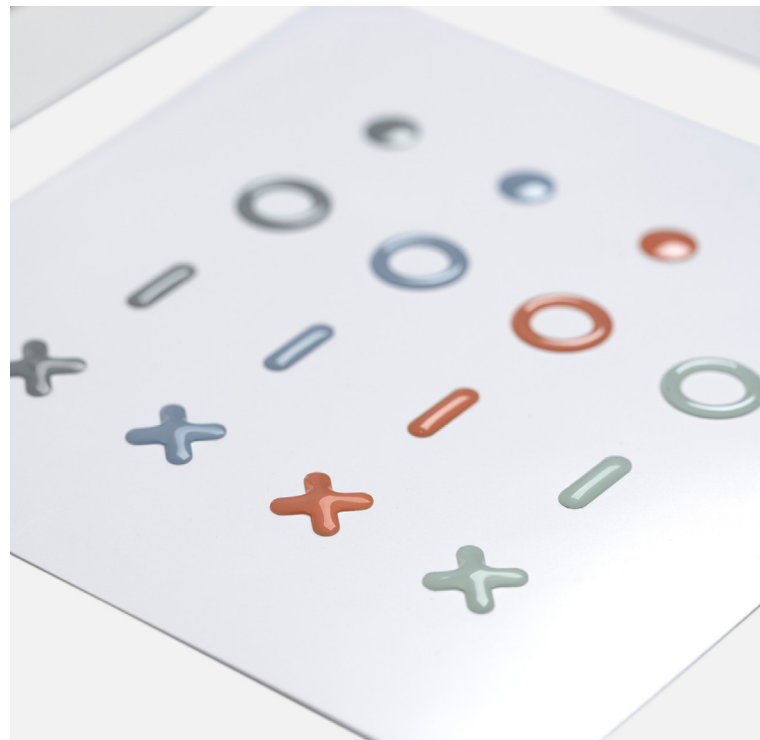
- **Read Aloud and Immersive Reader** for auditory learners or people who have dyslexia.
- **Accessibility Checker**, which helps users create inclusive documents.
- **Keyboard shortcuts and dictation tools** for hands-free productivity.

MICROSOFT ADAPTIVE ACCESSORIES: CUSTOM HARDWARE FOR INDIVIDUAL NEEDS

In 2022, Microsoft introduced a new line of **Adaptive Accessories**, including:

- **Adaptive Mouse:** Modular and customizable for comfort and control.
- **Adaptive Hub:** A central connection device for multiple inputs.
- **Adaptive Buttons:** Programmable controls that can be used with 3D-printed attachments.

These tools were designed in response to feedback from users who found traditional keyboards and mice painful or impossible to use. The modularity allows individuals to create a **setup that reflects their body and needs**, not a one-size-fits-all solution. Together, these features help create more digital workspaces, promoting involvement in education, employment, and creative industries.





THE ROAD AHEAD

While Microsoft has made incredible strides, it continues to evolve. New AI-powered tools, haptic feedback technologies, and expanded partnerships are on the horizon, pushing the limits of what's possible in accessibility tech. Microsoft's adaptive tools are breaking down barriers in both gaming and productivity through thoughtful design, customization, and a people-first approach. As this movement grows, the message is clear: **when technology adapts to people, not the other way around, everyone wins.**

To learn more or create a custom adaptive hardware system, please visit <https://support.microsoft.com/en-us/adaptiveaccessories>

WHY IT MATTERS

According to the World Health Organization, over 1 billion people globally experience or have some form of disability. That's **one in seven people**—and their full participation in life, work, and play shouldn't depend on workaround solutions or exclusionary design.

By integrating these ideas into mainstream products, Microsoft is proving that adaptation doesn't mean compromising on performance or style—it means enhancing the user experience for everyone.



BEYOND THE PAIN: NAVIGATING CRPS AND THE REALITY OF AMPUTATION



For those living with Complex Regional Pain Syndrome (CRPS), every day can feel like a battle—one marked by burning pain, hypersensitivity, swelling, and emotional exhaustion. While not widely known, CRPS has often been described by patients as one of the most painful conditions in existence. CRPS not only affects the body but can dominate every aspect of a person's life. When all other treatments fail and the pain becomes too much to bear, some people with CRPS make the complex, deeply personal, and sometimes even controversial decision to consider amputation of an otherwise healthy limb.

WHAT IS CRPS?

Complex Regional Pain Syndrome is a chronic neurological condition usually triggered by injury or trauma—sometimes even something as minor as a sprain or fracture. The pain is **disproportionate to the original injury**, often accompanied by changes in skin color and temperature, swelling, limited mobility, and extreme sensitivity to touch or temperature. There are two types:

- **Type I (formerly Reflex Sympathetic Dystrophy):** No confirmed nerve damage.
- **Type II (formerly Causalgia):** Identified nerve injury.

CRPS is often described as an invisible and misunderstood illness. Diagnosis can be delayed, and treatments—ranging from nerve blocks and medications to physical therapy and spinal cord stimulators—don't work for everyone.

WHEN PAIN BECOMES UNLIVABLE

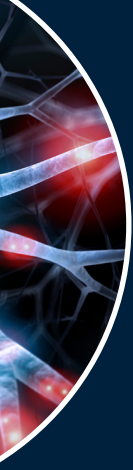
For some people, CRPS becomes so severe and unmanageable that they consider amputation as a last resort. While it may seem counterintuitive to remove a limb to relieve pain, the reality is that for many, it's not about eliminating the pain entirely—it's about reclaiming a life that has been robbed by constant suffering.

This decision is never made lightly. It comes after years—sometimes decades—of enduring relentless pain and trying every known treatment without relief. It involves complex conversations with doctors, mental health professionals, family, and others living with CRPS.

THE DECISION TO AMPUTATE: HOPE, FEAR, AND REALITY

Choosing amputation to treat CRPS is filled with uncertainty. While some people experience significant relief after amputation, others continue to face **phantom limb pain or recurrence of CRPS in the residual limb**. This phenomenon—known as **CRPS recurrence or “spreading”**—is a real risk that must be weighed carefully.

However, for some, amputation leads to a sense of freedom they hadn't felt in years. It may open the door to prostheses, mobility, and the possibility of participating in life in ways that felt impossible while living with the constant torment of CRPS.



“Amputation didn’t cure my pain completely, but it gave me something I thought I’d lost forever—hope,” shares one patient who has CRPS. “I started setting goals again, dreaming again. That was worth everything.”



THE IMPORTANCE OF WHOLE-PERSON CARE

Whether someone chooses amputation or continues with other treatments, one thing is clear: navigating CRPS requires a comprehensive care plan. This plan may include:

- **Pain management** with medication, nerve blocks, or implants.
- **Physical therapy** to preserve mobility and function.
- **Mental health support** for depression, PTSD, and anxiety.
- **Peer support** to connect with others who understand the unique challenges of CRPS.
- **Integrated care teams** including pain specialists, prosthetists, surgeons, and rehabilitation experts.

LIFE AFTER AMPUTATION: REDEFINING POSSIBILITY

Life after amputation for someone with CRPS is complex, but it can also be deeply fulfilling. Many find new purpose through adaptive sports, advocacy, creative expression, or peer mentorship. While challenges remain, the shift from surviving to thriving can be life-changing.

But whether continuing to fight CRPS with emerging therapies or making the decision to amputate, each person’s journey deserves to be heard, honored, and supported.

How Common is CRPS?

- 5-26 per 100,000 people annually

Who and How are People Affected?

- Female to Male ratio ~ 3.4 – 4:1
- Mean age of onset: 47–53 years

Type I vs Type II

- 90% Type I (no confirmed nerve injury)
- 10% Type II (with confirmed nerve injury)

After Injury

- Up to 8.8% after distal radius fracture

Global post-injury prevalence:

- 3.04% (12 months),
6.46% (24 months)

Where in the Body?

- 67% Hand / Wrist
- 22.6% Foot / Ankle

Key Symptoms Reported

- Temperature difference: 98%
- Movement limitation: 93.7%
- Swelling: 91.8%

SOURCES

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SCLERODERMA AND RAYNAUD'S:

SHEDDING LIGHT ON THEIR OVERLAP AND NAVIGATING THE PATH TO PROSTHETIC DEVICE POSSIBILITIES

AN ACNC24 EVENT RECAP

When it comes to autoimmune and vascular disorders, two conditions often discussed together—but not always well understood—are scleroderma and Raynaud's phenomenon. Though different in origin and severity, these conditions frequently overlap and can lead to serious complications, including tissue damage, digit loss, and in some cases, the need for **partial or full limb amputation**.

Understanding their connection is key to early intervention, appropriate care, and in severe cases, a smoother path toward **prosthetic rehabilitation**. This article sheds light on the link between the two, their progressive nature, and how individuals can reclaim function and independence through personalized prosthetic solutions.

UNDERSTANDING THE CONDITIONS

What Is Scleroderma?

Scleroderma, also known as systemic sclerosis, is a chronic autoimmune disease characterized by the hardening and tightening of the skin and connective tissue. It can be localized (affecting just the skin) or systemic (impacting internal organs such as the heart, lungs, and kidneys).



Key symptoms include:

- Skin thickening, especially in fingers and hands.
- Joint stiffness and pain.
- Fatigue and muscle weakness.
- Digestive and pulmonary complications in more severe cases.

Scleroderma varies widely in how it presents—from mild and manageable to life-threatening.

What Is Raynaud's Phenomenon?

Raynaud's is a vascular condition marked by **extreme sensitivity to cold or stress**, leading to the narrowing of small blood vessels in the fingers, toes, ears, or nose. It causes a characteristic color change—white (lack of blood flow), blue (lack of oxygen), and red (return of blood)—often accompanied by **numbness, tingling, or pain**.

Raynaud's can be:

- **Primary (idiopathic)** – occurring on its own.
- **Secondary (disease-associated)** – most commonly linked to scleroderma and other autoimmune conditions.



THE OVERLAP: WHEN SCLERODERMA AND RAYNAUD'S COLLIDE

More than **90% of people with scleroderma experience Raynaud's symptoms**, often as one of the earliest signs. In fact, severe Raynaud's in a patient with other autoimmune symptoms is a red flag for systemic scleroderma.

Over time, restricted blood flow in the fingers and toes can cause tissue death. Combined with scleroderma's impact on skin integrity and immune function, the result can be **non-healing wounds, chronic infection, and amputation** of fingers or limbs.

THE EMOTIONAL AND PHYSICAL TOLL OF AMPUTATION

When amputation becomes necessary due to scleroderma and Raynaud's, it often follows a long road of pain, limited function, and repeated interventions. The emotional toll can be just as profound as the physical loss.

“Finding this beautiful community was the perfect time. It has taught me so much to hear about people's experiences. Everyone has a different story but together we thrive.” Kim G.

Many patients report:

- A sense of **grief or identity loss**.
- Concerns about appearance and function.
- Anxiety around prosthesis use or phantom limb pain.

That's why early, **whole-person support** is critical—from mental health counseling to occupational therapy and peer connection.

NAVIGATING PROSTHESIS POSSIBILITIES

The good news: prosthetic technology has advanced significantly, and there are **specialized solutions for partial hand, finger, and toe loss**. Whether through cosmetic silicone prostheses for aesthetic restoration or functional devices designed to restore grip, pinch, or dexterity, individuals with scleroderma and Raynaud's-related amputations have options.

Key Considerations:

- **Residual limb care** is essential, especially due to fragile skin and poor circulation.
- **Lightweight, breathable materials** can reduce skin irritation.
- **Custom finger and hand prostheses** are available, including passive (for appearance) and active (for function) options.
- **Voice-activated, myoelectric, or body-powered systems** may be considered for more extensive limb loss.

Multidisciplinary Care

Successful prosthesis integration requires a team: prosthetists, rheumatologists, dermatologists, physical therapists, and mental health providers. Together, they can ensure the prosthesis supports function without compromising skin health or circulation, both of which are at risk in scleroderma and Raynaud's patients.

THE IMPORTANCE OF ADVOCACY, AWARENESS, AND CONNECTION

Living with these conditions can feel isolating, which is why raising awareness and sharing stories is vital. But awareness alone isn't enough—it's awareness combined with connection that makes the difference. Organizations like the Scleroderma Foundation and Raynaud's Association offer resources and research updates.

Connecting to the right information, professionals, and community support helps people navigate challenges like managing fragile skin, finding the right prosthesis fit, or coping emotionally. Each shared experience lightens the path forward.

Many still assume the Amputee Coalition only represents those who lost limbs to injury or cancer. In truth, it serves anyone who has limb loss and/or limb difference, and anyone who may have an amputation or be born having a congenital limb difference— including those whose stories begin with conditions like scleroderma, Raynaud's, or congenital limb difference. That acceptance matters. It ensures that no matter how different the journey looks, there is a place to turn for guidance and support.

The Coalition provides more than encouragement—it offers practical tools, peer

insights, and access to the latest prosthetic technologies. Together, members exchange knowledge, solve problems, and build momentum. It's not just a community—it's a framework for moving forward, knowing no one has to navigate this path alone.

Editors note: Demeshia Montgomery is the woman on the right on page 15 who recently passed. Our hearts go out to Deme's loved ones. Her impact will long be remembered. Her ear to ear smile, voracious passion, and compassionate grit made us all want to do more and do better. Deme's resourceful and knowledgeable interactions have supported countless individuals at various points in their journey and we are grateful to having known her. May Deme's soul find peace. 1981-2025.

SCLERODERMA & RAYNAUD'S: KEY STATS AT A GLANCE

- **Scleroderma affects about 300,000 Americans.** Women are about **4 times more likely** to develop it than men. (Scleroderma Foundation, SclerodermaInfo.org)
- **Worldwide**, scleroderma occurs in about **17 out of every 100,000 people**, with about **1–2 new cases per 100,000 each year**. (Oxford Rheumatology, 2021)
- **Raynaud's phenomenon** (the circulation disorder causing fingers/toes to turn white/blue in cold or stress) affects about **5% of people worldwide**. (Oxford Rheumatology, 2024)
- Almost **90% of people with scleroderma also experience Raynaud's**. (Scleroderma Research Foundation)
- For people who first develop **Raynaud's without another condition**, about **1 in 8 later develop an autoimmune disease**, often scleroderma. (JAMA Internal Medicine)

THE ROAD TO RECOVERY: THE UNTOLD STORY BEHIND THE FILM DRIVING MRS. M

A Standout Presentation from ACNC24

Among the deeply moving presentations at the **Amputee Coalition National Conference 2024 (ACNC24)**, was “**The Road to Recovery: The Untold Story Behind the Film Driving Mrs. M.**” Told with raw honesty and creative vision, the story behind this upcoming documentary captivated the ACNC24 audience, illustrating the power of human compassion lessons from a third grade class and storytelling rooted in lived experience.

FROM COLD TO CATASTROPHE: A TRUE STORY THAT SPARKED A FILM

It all began with a third-grade teacher, a classroom cold, and a life turned upside down. What started as a routine illness escalated into a medical emergency so severe that it resulted in the **loss of both arms and legs**. Her story caught the attention of filmmaker **Connie Bottinelli** when an 8-year-old girl shared her distress about her beloved teacher.

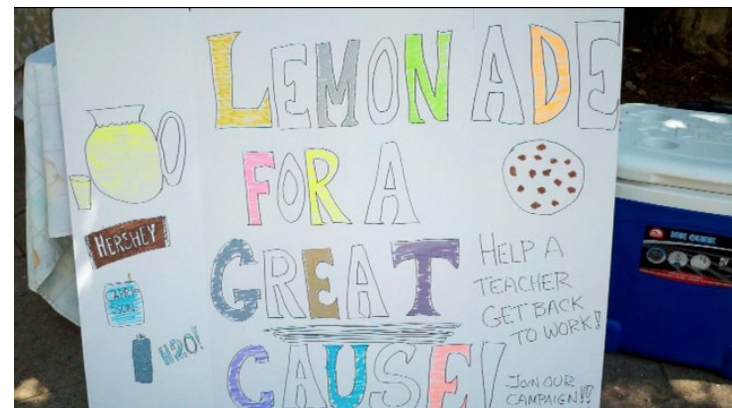
Out of that child’s heartbreak grew a 9-year documentary journey that would become **Driving Mrs. M**—a feature-length film chronicling one woman’s determination to **reclaim her**



independence, redefine her purpose, and teach again despite profound physical loss and systemic barriers.

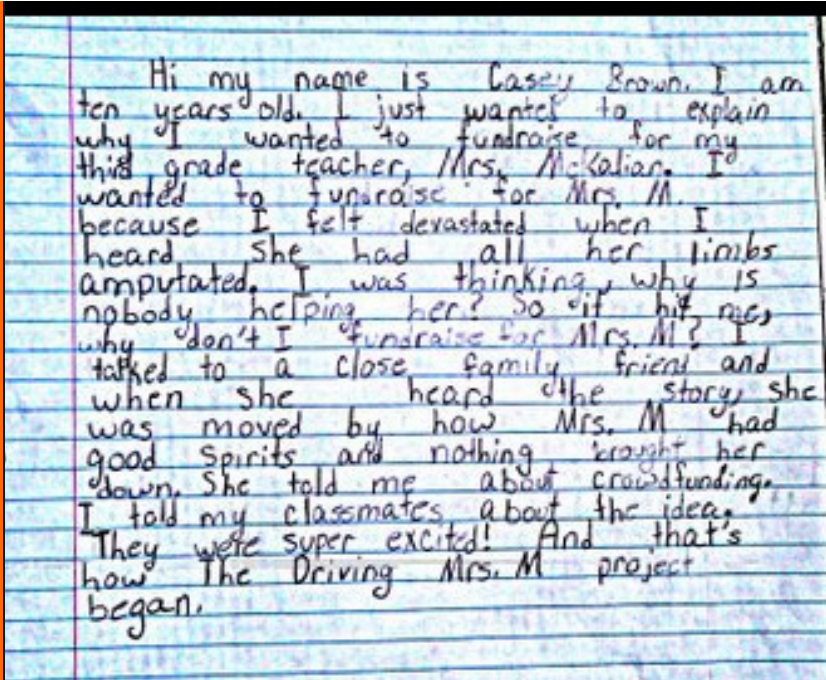
STUDENTS WHO WENT ROGUE—AND A SYSTEM THAT LET HER DOWN

As the story unfolded at ACNC24, attendees



learned that the teacher—lovingly known as Mrs. M—was unexpectedly terminated from her job due to her sudden limb loss. In defiance of school district policies, **her students took matters into their own hands**, organizing a fundraiser to support the teacher who had once supported them.

This act of youthful leadership and loyalty became a central thread in the film's development: the unshakable bond between a teacher and her students, and how that connection fueled a true comeback story.



"Hi my name is Casey Brown. I am ten years old. I just wanted to explain why I wanted to fundraise for my thrid grade teacher, Mrs. Mikaelian. I wanted to fundraise for Mrs. M because I felt devastated when I heard she had all her limbs amputated. I was thinking why is nobody helping her? So it hit me, why don't I fundraise for Mrs. M? I talked to a close family friend and when she heard the story, she was moved by how Mrs. M had good spirits and nothing brought her down. She told me about crowdfunding. I told my classmates about the idea. They were super excited! And that's how The **Driving Mrs. M** project began."

A PRODUCTION TEAM THAT BELIEVES IN THE MISSION

Filmmaker **Connie Bottinelli**, an Emmy-winning director and producer, has spent nearly a decade documenting Mrs. M's journey. At ACNC24, Bottinelli and her team—including composer **John Keltonic**, sound mixer **Tommy Vicari**, and story consultant **Geoffrey Smith**—shared the emotional labor and creative process behind the scenes: from long editing hours and grant writing to piecing together nine years of footage.

They emphasized that *Driving Mrs. M* is not just a film—it's a **platform for advocacy**, highlighting the intersection of disability, human rights, and the urgent need for support systems.

DISABILITY IS NOT THE END—IT'S THE BEGINNING OF WHAT'S NEXT

One of the most powerful messages shared during the ACNC24 session

was that **living with a disability doesn't diminish a person's value, vitality, or voice**. In fact, Mrs. M's life after amputation became a springboard for innovation and advocacy. The film's tagline says it all:

"Children do the impossible because they don't know they can't."

A CALL TO ACTION: JOIN THE JOURNEY

With generous grants and \$15,000 in private support already raised, the *Driving Mrs. M* team is closing in on the last part of the funding needed to complete the film's edit. Every tax-deductible donation supports post-production needs, including editing, music composition, and accessibility features.

To support or learn more about the film, visit the official campaign page: Facebook.com/DrivingMrsM/

OPRA IMPLANT: A NEW ERA IN BONE-ANCHORED PROSTHESES AND MOBILITY

Featuring Highlights from Integrum's OPRA event at ACNC24

The Orthotic & Prosthetic field has undergone a tremendous transformation, but few innovations have proven as life-changing as osseointegration or the **OPRA Implant System**. Developed in Sweden, OPRA—short for **Osseointegrated Prostheses for the Rehabilitation of Amputees**—is a **bone-anchored prosthetic system** that eliminates the need for traditional socket suspension, offering new levels of comfort, stability, and mobility.

By anchoring directly to the residual limb's bone, the OPRA system offers those who have limb loss a stronger connection to their prosthesis, improved range of motion, and enhanced quality of life.

WHAT IS THE OPRA IMPLANT?

The OPRA Implant consists of a titanium implant inserted into the **medullary canal of the bone** (most commonly the femur for above-knee amputations). This implant integrates with the bone through a biological process called **osseointegration**, allowing an abutment to protrude through the skin and connect directly to an external prosthesis.

This eliminates the need for a prosthetic socket—which often causes discomfort, skin irritation, and limited movement—and provides a **stable, skeletal attachment** for the limb.

THE SCIENCE BEHIND OSSEOINTEGRATION

Osseointegration was first pioneered in dental implants by **Dr. Per-Ingvar Brånemark**, who later adapted the technology for orthopedic use. The OPRA system takes advantage of titanium's biocompatibility and ability to fuse with living



bone without causing rejection or long-term inflammation.

By transmitting load forces directly through the bone—as a biological limb would—the system enables users to experience **enhanced proprioception**, or the sense of how their body moves in space.

BENEFITS OF THE OPRA SYSTEM

- 1. No More Sockets** - Conventional prostheses rely on custom-fitted sockets, which can be uncomfortable, sweaty, and difficult to maintain. The OPRA system removes this barrier entirely.
- 2. Improved Mobility** - Studies show users of bone-anchored systems report improved walking ability, especially over uneven terrain and long distances.
- 3. Greater Range of Motion** - Unlike sockets, which restrict movement around the hip or shoulder, the OPRA implant allows for natural joint mobility.
- 4. Easier Attachment and Removal** - Users can attach or detach their prosthesis in

seconds, without adhesives, liners, or special techniques.

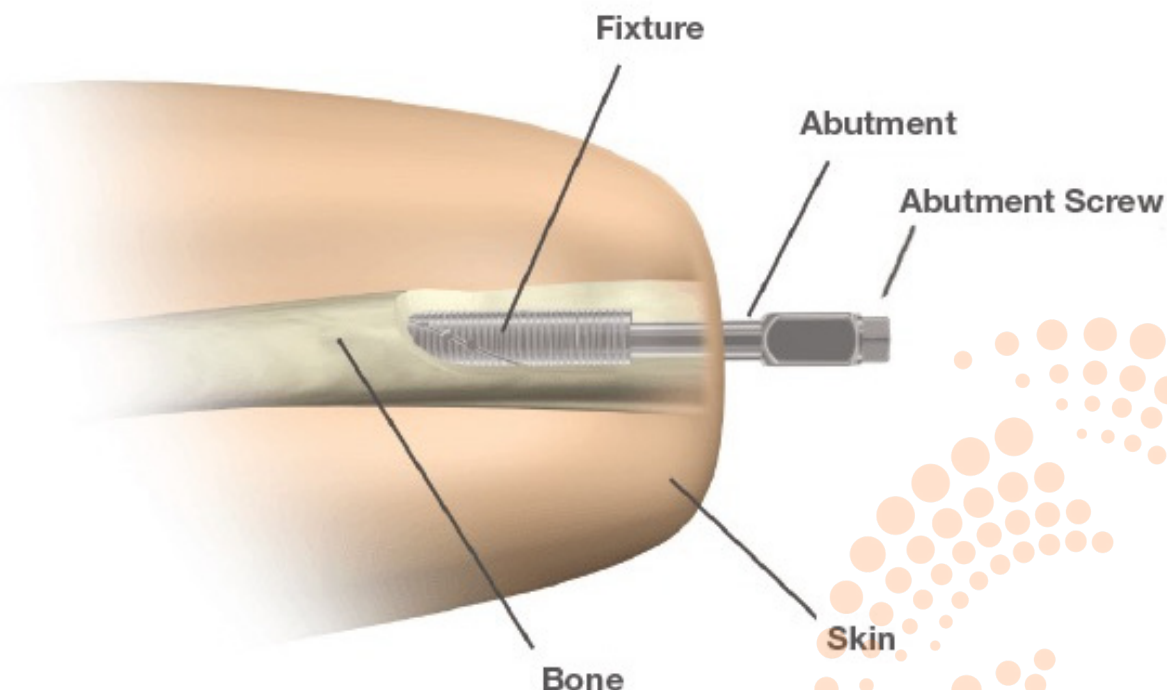
- 5. Enhanced Proprioception** - Many patients report a greater sense of limb position and control, which can improve their balance and confidence.

GLOBAL USE AND FDA APPROVAL

The OPRA system has been successfully used in Sweden and Europe since the 1990s. After over 20 years of clinical study and refinement, it received U.S. FDA approval in December 2020 for people who have above-knee limb loss who cannot use socket prostheses.

Approval was granted under the Humanitarian Device Exemption (HDE) program, based on evidence of safety and probable benefit.

“This approval offers a new alternative for individuals who have not been able to benefit from traditional socket prosthetics.”
— U.S. Food and Drug Administration (2020)



WHO IS A CANDIDATE?

According to Integrum, the manufacturer of OPRA, ideal candidates include:

- Those who have had transfemoral (above-knee) or transhumeral (above-elbow) amputations.
- Individuals who experience discomfort, instability, or skin breakdown with sockets.
- Those in good general health with sufficient bone volume and healing capacity.

All candidates must undergo a **two-stage surgical procedure**:

- **Fixture placement** (implant inside bone).
- **Abutment connection** (after bone integration).

WHAT'S NEXT FOR OSSEOINTEGRATION?

As research advances, engineers and surgeons are exploring the next frontier: **mind-controlled prostheses**. By integrating electrodes into the bone or nerves, future systems could enable wearers to control artificial limbs using **natural brain signals**, a concept currently in early clinical trials in Sweden and the U.S.

Note for Readers:

While the OPRA Implant system is one widely recognized provider of osseointegration technology, it is not the only option available. There are multiple surgical centers and manufacturers worldwide offering bone-anchored prostheses systems. Individuals are strongly encouraged to **conduct thorough research, consult with multidisciplinary clinical teams, and explore all available options** to determine the best fit for their individual needs, health status, and goals.

Additionally, the **Amputee Coalition's Scientific**

& Medical Advisory Committee (SciMAC) task force is actively developing a comprehensive **guide to osseointegration**, aimed at helping individuals better understand the process, risks, benefits, and access pathways, expected to publish in 2026.

Stay tuned for updates—**and to learn more about this innovative technology, join us at ACNC26**, where we'll continue exploring cutting-edge solutions for the limb loss and limb difference community.

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JOIN US FOR MOBILITY DAYS 2025 - EXPERIENCE THE POWER OF MOVEMENT

Get ready! So Every BODY Can Move is bringing **Mobility Days** to two cities in 2025—and we want **YOU** to be part of it. These free, high-energy, one-day events are all about movement, access, and community for individuals with limb loss and limb difference—and the volunteers who power the day.



- **Try sport/activity prostheses and orthoses**—run, swim, stretch, and explore new ways to move.
- **Learn your rights under SEBCM laws** and how to get activity-specific devices through insurance.
- **Get expert support** from prosthetists, orthotists, physical therapists, and adaptive coaches.
- **Connect with a vibrant community** of peers, clinicians, and advocates.

In **2025**, we're aiming to reach **100+ participants and volunteers**—and we want YOU on this journey. Whether you're an athlete, a first-time mover, a caregiver, or a clinician, Mobility Days is for you.

MARK YOUR CALENDAR

New Mexico – October 25: [Register Here](#)

Maryland / Mid Atlantic – December 6: [Register Here](#)

**SO EVERY BODY
CAN MOVE**



Impact in Action:

At last year's New Mexico Mobility Day, over 35 individuals experienced the freedom of movement—many for the first time. **Noemi Gallegos** ran for the first time in 40 years. Dow Hohlmayer described it as “freedom.” And for 71-year-old **Bill Arroyo**, swimming again after his amputation gave him the confidence to take on “bigger and bigger challenges.”

Be part of the movement. Sign up today and take your next step with us.



IMPORTANT FEDERAL FUNDING UPDATE: PROTECTING CRITICAL RESOURCES FOR OUR COMMUNITY



**amputee
coalition**™

At this time, even with the government shutdown, the Amputee Coalition is not impacted and remains optimistic that the federal budget for 2026 (FY26) will be agreed upon by Congress and passed soon. As shared in recent messaging related to AC Funding Updates, the House LHHS Appropriations Subcommittee and the Senate Appropriations Committee approved their respective spending bills for FY26, which include level-funding for the National Limb Loss Resource Center as of September 10th. We will continue to monitor the situation and provide updates as appropriate.

Your Voice Matters:

This is still the perfect time to take action.

[Take the National Limb Loss Resource Center survey today.](#)



As a reminder, funding for the National Limb Loss Resource Center provides lifesaving programs and services, including information and referral services, peer visit matching, virtual support groups, certified peer visitor training, limb loss limb difference education days, youth programming, resource development, workforce development, along with outreach and education across the nation. The Limb Loss Resource Center funding also subsidizes our work with the VA and DoD in service to our Nation's Veterans and active-duty servicemembers, their families, and caregivers.

**THANK YOU FOR YOUR CONTINUED SUPPORT FOR THE LIMB LOSS
AND LIMB DIFFERENCE COMMUNITY AND THE AMPUTEE COALITION.**

SUPPORT THE AMPUTEE COALITION

Why Your Support Matters

As a donor-supported nonprofit, your gift—tax-deductible to the extent allowed by law—helps sustain services for the 5.6 million people in the U.S. who have limb loss or limb difference. Each year, tens of thousands rely on the Resource Center for support, connection, and critical resources.

Core Services Your Gift Supports

- **Information & Referral** – Trusted guidance and access to essential resources.
- **Peer Support & Support Groups** – 231+ groups nationwide and Certified Peer Visitors (CPVs) who provide encouragement to individuals, families, Veterans, and active-duty military.
- **Education & Outreach** – Workshops, sports clinics, and webinars on adaptive tech, pain management, workforce, and more.

Now is the Time to Give

Your donation ensures these life-changing services continue without interruption. Every gift makes an impact—keeping support, education, and advocacy available for those who need it most.

PLEASE DONATE TODAY!



OTHER WAYS TO GET INVOLVED

You are essential to protecting and strengthening services for the limb loss and limb difference community:

- **Contact Congress** – Urge lawmakers to fund the National Limb Loss Resource Center in FY26.
- **Share Your Story** – Personal stories drive change; submit yours to the Coalition or tag Congress on social media.
- **Become a CPV** – Volunteer to support individuals through their journey.
- **Join Our Advocacy Network** – Sign up for alerts and be ready to act when your voice is needed.
- **Attend ACNC26** – Celebrate our 40th anniversary in Las Vegas with community, education, and advocacy.

Together, we can ensure vital services remain strong for years to come.

25 Massachusetts Ave NW, Suite 650
Washington, DC, 20001

NATIONAL LIMB LOSS RESOURCE CENTER®

Where can you go when you have questions about limb loss or limb difference? Here at the National Limb Loss Resource Center®, we provide comprehensive information and resources free of charge. Information is developed and reviewed by the Resource Development team and the Scientific and Medical Advisory Committee (SciMAC) who are experts in the field of limb loss and limb difference. This ensures accuracy of the information being provided.



Connect with a resource center specialist to request materials or discuss your needs with a Healthcare Navigator. Our knowledgeable team is the place to turn to when you have questions about your journey in limb loss and limb difference. You can reach them by calling toll-free 888/267-5669 or by completing our secure online intake form at **[Amputee-coalition.org/service/find-support-services](https://amputee-coalition.org/service/find-support-services)**

Call **Toll-Free 888/267-5669, Ext. 1** to speak with an information specialist
8 AM - 5 PM Eastern, Monday-Friday.

