



The Honorable Rosa DeLauro
Chairwoman
House Appropriations Subcommittee
on Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
House Appropriations Subcommittee
on Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20515

The Honorable Patty Murray
Chairwoman
Senate Appropriations Subcommittee
on Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20510

The Honorable Roy Blunt
Ranking Member
Senate Appropriations Subcommittee
on Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20510

May 2, 2022

Dear Chairwomen DeLauro and Murray and Ranking Members Cole and Blunt:

On behalf of the 2.1 million Americans living with limb loss and limb difference and the 28 million more at risk, the Amputee Coalition thanks you for your long history of bipartisan support for the National Limb Loss Resource Center funded through the Administration for Community Living (ACL). The Amputee Coalition is the only national nonprofit representing the limb loss and limb difference community, and it has operated the National Limb Loss Resource Center since its establishment by Congress in 1997. The Center provides education, information, support services, and resources for people living with limb loss and limb difference thanks to funding not found anywhere else in the federal budget. This investment has been vital for our community and has been especially true during the COVID-19 public health emergency. We have outlined below some of the successes of the past year and the continued need to serve our community. **To meet the needs of the community and reach and serve all members of the limb loss and limb difference community, no matter who they are or where they live, the Amputee Coalition respectfully requests \$4.2 million in Fiscal Year 2023 funding for National Limb Loss Resource Center.**

The Amputee Coalition is currently in year four of a five-year cooperative agreement to operate the National Limb Loss Resource Center with the ACL, thanks to Congressional support and funding. The organization seeks to reach out to and empower people living with limb loss and limb difference to achieve their full potential through education, support, advocacy, and to promote limb loss prevention. We would like to share why we are so proud of the work the National Limb Loss Resource Center has done to serve the limb loss and limb difference community, how we have responded to the challenges of the COVID-19, and what lies ahead.

How the National Limb Loss Resource Center Serves the Limb Loss and Limb Difference Community

The National Limb Loss Resource Center (NLLRC) is the go-to resource for people who experience

limb loss or are born with limb difference. In Fiscal Year (FY) 2022, the NLLRC served 1.3 million Americans with limb loss and limb difference. This represents over 60 percent of the limb loss and limb difference community. The NLLRC has a wide reach, and we serve these Americans through various outlets, to include:

- Direct service to members contacting NLLRC
- Peer visitations
- Limb Loss and Limb Difference Awareness Month engagements
- National Conference
- Information obtained on NLLRC website
- Support groups
- Training of individuals to serve in various volunteer capacities
- *inMotion* Magazine publications
- Increased hospital partnerships

Each year, the NLLRC – as the only information and referral center for the community -- disseminates over 30,000 patient education materials created by the program. These resources promote amputation prevention, physical and emotional recovery, rehabilitation expectations, community and career reintegration, independent living, physical and mental health, and how to navigate the challenges of the limb loss journey. During the last year, we were able to publish an online advocacy training course that will spread the reach of the NLLRC and positively impact the lives of Americans living with limb loss and limb difference.

NLLRC continues to maintain the newly launched 24/7/365 online library of national, state, and local resources. With expert, certified resource center staff available by phone and social media, community members can find the information, experts, and other resources they may need whenever they have a moment to ask for help, and through whatever mechanism feels most comfortable.

The NLLRC also runs the nationally recognized and evidence-based Certified Peer Visitor program with more than 1,500 volunteers who provide one-on-one support to make sure that nobody goes through the journey of recovery and readjustment alone. It supports a network of over 420 support groups across the country to give people a regular sense of community — including virtual support groups introduced in 2020, which have proven crucial during the social isolation of the COVID-19 pandemic. NLLRC also connects a growing list of more than 90 hospital partners who have embedded the Amputee Coalition’s peer support programs and informational resources to ensure patients receive them in the clinical setting immediately after their amputation surgery. In addition, the NLLRC supports our veterans and active-duty military personnel through partnerships and volunteer programs with the Department of Veterans Affairs (VA) and the Department of Defense (DoD).

Responding to the COVID-19 Public Health Emergency

During the pandemic, the NLLRC’s services were needed more than ever. People living with limb loss and limb difference are at higher risk for COVID-19 infection because the same underlying health conditions that most often result in amputation, such as diabetes, Peripheral Artery Disease (PAD), and cancer, are the same conditions that make people more vulnerable to COVID-19. In fact, due to delays in wound treatment like diabetic foot ulcers, and complications from COVID-19, such as severe blood clotting, early evidence shows that an increased number of amputations were performed during the pandemic. Even with much- appreciated improvements to telehealth options, COVID-19 has made it more difficult for people at risk for amputation and those living with limb loss and limb difference to access the care they need. In many cases, at- risk patients have forgone routine doctor’s visits that

might prevent amputation, including seeing specialists or seeking adjustments to assistive devices to prevent further limb damage. Worse still, social isolation has taken its toll on mental health and well-being across the community — particularly veterans with limb loss, whose suicide rates have increased.

To make sure people living with limb loss and limb difference continued to receive the supports they need, overcome social isolation, and stay safely distanced, the Amputee Coalition immediately transitioned the NLLRC's staff and fulfillment center to remote work, and transitioned its programs and services to virtual in March of 2020. We created new virtual support groups, which meet at 6:00 pm in rotating time zones each week to facilitate participation across the country. We also developed resources to “help the helpers” including a support group specifically for Support Group Leaders and Certified Peer Visitors, who experienced an increase in demand this past year. Likewise, an updated Peer Support App includes protected, in-app video and phone chat for virtual peer visits in the hospital (when in-person visits were not permitted), in rehabilitation centers, or at home. The Resource Center also developed new COVID-19 fact sheets and other informational materials supporting people living with limb loss and limb difference as they, like many others, navigated the challenges of the pandemic. Many NLLRC prevention resources have been in particularly high demand during the pandemic as individuals and health care providers have experienced delays in routine or urgent care. In addition, the Coalition ramped-up strategic partnerships to expand and improve care for mental health and emotional well-being. These innovative programs have been remarkably successful and will continue beyond the pandemic.

Expanding Virtual Programming

As a result of the pandemic, the organization has shifted much of its programming to virtual, which is essential to reaching and serving people living with limb loss and limb difference when in-person activities halted. While we successfully launched online and other remote programming, in many cases for the very first time, this migration of programming demanded significant resources, especially related to evolving programs to meet goals in virtual environments, stakeholder engagement, secure technology, and staff time. An unanticipated benefit has been reaching community members who otherwise have not been able to participate in our programs. We continue to seek ways to reach our community members where they are, and many members of our community have asked for the NLLRC's virtual programming to continue even once we are able to be back in person since virtual events provide important access and supports to our community members, many of whom mobility may be a challenge, especially those in underserved and rural communities. Moving forward, we are committed to maintaining and growing these programs. When public and safety guidance permits, we plan to host events that include both in-person and virtual participation to ensure we reach and serve the greatest number of people living with limb loss and limb difference. To do so, additional resources will be needed throughout the pandemic and beyond to make resources more accessible to those who need them.

Looking Ahead

As we look to FY 2023, the NLLRC can positively impact the lives of the limb loss and difference community and Americans at risk of amputation by increasing the reach of its resources, expanding virtual programming, understanding and working toward addressing health disparities, and growing partnerships and services.

Increasing Demand for Materials

The Amputee Coalition increased dissemination of NLLRC materials by over 65 percent from 2019 to

2020, and that growth is continuing in 2021. NLLRC fulfillment requests increased by 35 percent above last year's increase in demand, and requests for publications are already outpacing our inventory. Additionally, as we look to reach people where they are and when they most need us, the NLLRC is seeking to modernize dissemination methods and readability to support the full community, including underserved populations. Based on recent improvements in reach and methodology, we are providing more patients with the information, resources, and support they need before they leave the clinical setting. As you know, timeliness of patient information and support helps improve health outcomes. Scalable partnerships with the NLLRC continue to grow and, with them, the volume of our publications and other resources must keep pace to reach community members in need. To continue modernization and to meet the needs of the community, additional resources are needed.

Implementing Virtual Programming

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Understanding and Working Toward Addressing Health Disparities

The NLLRC recognizes that health disparities significantly impact our community, especially Black and Latino Americans who are at higher risk to lose a limb. For example, the rates of diabetes-related amputation are up to four times higher for Black Americans and up to two times higher for Latino Americans than for white Americans. We are committed to ensuring all Americans have access to high quality health care and resources, and with additional resources we seek to expand the NLLRC's stakeholder engagement and reach to historically underserved and underrepresented communities.

Growing Strategic Partnerships and Services

The Amputee Coalition's hospital partner network, which provides the NLLRC's valuable informational resources and peer support programs to patients immediately after their amputation surgery, has grown by nearly 600 percent. Partnerships with hospitals and providers allow us to connect patients to resources in the clinical setting and increase dissemination of our publications when and where they are needed most. We seek to continue to grow our strategic partnerships and further the reach of our resources to better serve all people living with limb loss and limb difference.

Improving Grassroots Advocacy Program

The Amputee Coalition employs a vast network of volunteer grassroots advocates throughout the country. This program provides an avenue to advocate for the community at the local, state, and federal levels of government. Moreover, we also provide training to understand and improve self-advocacy.

This is a critical element for members in our community as they engage with numerous public and private sector organizations, including government agencies, nonprofit organizations, and private sector insurance providers. Having representation in each state allows for a fuller understanding of the needs of the limb loss and limb difference community. Moreover, many grassroots advocates serve as certified peer visitors and bring a wealth of knowledge through lived experience and serving in their peer visitor capacity.

To become a lead advocate, a candidate must successfully complete the required advocacy training. In March 2022, we released an online advocacy course that provides lead advocates with the necessary tools to effectively advocate for the community. Through this accomplishment, potential advocates no longer need to incur the costs of traveling to receive this training; it also allows for the organization to reach a greater audience through the virtual training.

In April 2022, we improved the organization's grassroots advocacy program. Through creating a regional ambassador program, we now offer an opportunity for volunteer leadership that will prove to streamline the method we receive and deliver information to our advocates. This approach creates an avenue for volunteer mentorship to improve the effectiveness of the grassroots advocacy program. As we emerge from the COVID-19 pandemic, we seek to again hold regional conferences that will strengthen the efforts of the community and engage external stakeholders to spread awareness of the needs of the limb loss and limb difference community.

The National Limb Loss Resource Center supports millions of Americans with limb loss and limb difference to live healthier, safer, independent, and more fulfilling lives. The Amputee Coalition respectfully requests \$4.2 million for the National Limb Loss Resource Center to meet emerging opportunities to serve the community, including increased demand for publications and other resources, continuation of virtual programming, addressing health disparities, and growth of strategic partnerships. Thank you again for your leadership. This work would not be possible without your support and investment in these programs and services. Please do not hesitate to contact me with any questions or if we can be helpful to you and your constituents.

Sincerely,

A handwritten signature in blue ink that reads "Mary Richards". The signature is fluid and cursive, with the first name "Mary" being more prominent than the last name "Richards".

Mary Richards
President and
CEO Amputee
Coalition