



Advocacy Toolkit

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Standing Together Against Limb Loss (Standing TALL) is a national awareness campaign to engage patient advocacy, disease, minority, faith-based, veteran and professional organizations to increase understanding among policy makers, the media and the general public about the startling racial disparities that exist among American amputees. Far too many minority Americans experience limb removal because of vascular disease, which can be easily diagnosed and effectively treated to prevent amputation. **No one should experience limb loss unnecessarily.**

RACIAL DISPARITIES AMONG PAD PATIENTS AND AMPUTEES

Peripheral artery disease (PAD) is a limb-threatening circulatory condition, that when left undiagnosed and untreated can result in lower-limb amputation. It is exacerbated by conditions like diabetes, chronic hypertension and renal disease, which are most prevalent in minority populations.

African Americans and other minority populations in the U.S., including Native Americans and Hispanic Americans, have disproportionately higher rates of PAD and diabetes. Combined with limited access to community-based interventional treatments, these populations have measurably higher rates of avoidable amputation. Data show that many of these amputations can be prevented if clinically appropriate intervention occurs before an individual's limb is removed.

Standing TALL aims to end limb loss by advocating for policies to ensure that limb-salvaging procedures are completed before amputation occurs.

African Americans are **UP TO TWICE AS LIKELY** to be diagnosed with PAD than white Americans.

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Hispanic Americans are **50 TO 75 PERCENT** more likely to undergo an amputation than Caucasians.

.....

African Americans are **UP TO 4 TIMES MORE LIKELY** to have an amputation than white Americans.

.....

Native Americans are **TWICE AS LIKELY** to undergo an amputation as Caucasians.

.....

HOW TO STAND TALL:

- Join the Standing TALL Coalition
- Spread the word to your constituents
- Engage on digital platforms
- Activate your grassroots
- Become a thought leader
- Ask lawmakers to take part

BOTTOM LINE: WE MUST STAND TALL TO END LIMB LOSS DISPARITIES IN AMERICA.

II. KEY TALKING POINTS

OVERVIEW

- Minorities, especially people of African American, Hispanic American and Native American descent, are at greater risk for losing a limb in the U.S. than their Caucasian counterparts.
- Preventable amputations among minority populations are primarily related to diabetes and peripheral artery disease (PAD), which are both highly manageable conditions with appropriate clinical intervention and treatment.
- Discrepancies in amputation rates among minority groups when compared to white Americans demonstrate a critical need for action to ensure limb preservation is prioritized among clinicians and policy makers alike.
- The Standing TALL campaign seeks to reduce unacceptable limb loss in America.

KEY FACTS

- Minority populations in the U.S. have measurably higher amputation rates:
 - African Americans are up to 4 times more likely to experience an amputation than Caucasians.
 - Hispanic Americans are up to 75% more likely to experience an amputation than Caucasians.
 - Native Americans are twice as likely to experience an amputation than Caucasians.
- Data show as many as 500 Americans lose a limb each day in the U.S.
- Amputees experience increased rates of depression, healthcare spending and mortality that individuals whose limbs are spared.
 - Data show 71% of amputees are dead within three years of amputation.
- Amputation is the 6th most expensive surgery in the U.S., resulting in a macroeconomic cost of \$10.6 billion annually.

THE SOLUTION

- Innovative procedures and technologies exist that specifically prevent limb loss, however minority populations are not accessing this clinically appropriate care. Steps must be taken to improve access to limb-saving treatments for these populations.
- Policy solutions that increase awareness and access to limb saving procedures among minority populations could reduce amputations, decrease healthcare spending and dramatically improve lives.
- We are urging policy makers to support efforts to address the alarming limb loss discrepancies in American today.

III. SAMPLE MEDIA PRODUCTS

Consider submitting a letter to the editor (LTE) to your local newspaper to raise awareness about racial disparities in limb loss in your community. A letter to the editor is an excellent way to get the attention of your local leaders and call on them to act. To submit a letter, call your local newspaper and ask them for instructions. Letters can typically be submitted easily via email.

SAMPLE PATIENT LTE

Dear Editor,

Receiving a diagnosis of Peripheral Artery Disease (PAD) was devastating, as PAD is a circulatory condition where arteries are narrowed, reducing blood flow to limbs and increasing the risk of lower limb amputation. Fortunately, my condition was caught early and I could access an innovative procedure designed specifically to clear the blockage and save my lower leg. This, combined with routine care, means my diagnosis is manageable and the risk of limb loss is much smaller.

However, this is not the case for every patient with PAD. Minority populations experience limb loss at a significantly higher rate than their Caucasian counterparts. Specifically, African Americans are up to four times more likely to have an amputation than white Americans, Native Americans are twice as likely to undergo an amputation as Caucasians and Hispanic Americans are 50 to 75 percent more likely to undergo an amputation when compared to Caucasians.

But there is hope. Recent data show that these amputations can be prevented if patients receive timely, appropriate interventional care, like I did. Therefore, I urge our Congress and the Administration to create policies that increase access to care and put an end to limb loss disparity in America. There is no reason for someone to lose a limb because of limited access to care when we know amputations can be prevented.

If policies were enacted that made it easier for minority populations to access limb-saving procedures, amputations could be prevented and lives could be saved.

Name

City, State

SAMPLE PHYSICIAN LTE

Dear Editor,

As many as 18 million Americans are at risk for losing a limb due to Peripheral Artery Disease (PAD), a potentially life-threatening circulatory condition that when left undiagnosed and untreated can result in lower limb amputation. Perhaps more concerning is the fact that when compared to white Americans, African Americans are up to four times more likely to have an amputation and Hispanic Americans are up to 75 percent more likely to undergo an amputation because of PAD and related conditions like diabetes.

Both PAD and diabetes disproportionately affect minority communities. Combine this with the fact that African and Hispanic Americans have limited access to community-based interventional treatments and you have the perfect storm for increased amputations and mortality.

These statistics are incredibly troubling as a physician, as data demonstrate that a large majority of these amputations can be prevented if clinically appropriate intervention occurs before an individual's limb is removed. And by saving limbs, we can save more lives.

It's imperative that Congress and the Administration work to craft policies that ensure limb saving procedures are completed before amputation occurs in any population - especially minorities that studies show are systematically treated differently for limb-threatening conditions. There is no medical reason why certain groups of people should undergo a life altering procedure for a treatable condition.

I urge lawmakers to look closely at amputation trends in the U.S. and commit to working with the patient and physician communities to advance solutions that prevent amputation when alternative, limb-saving treatments are an option.

Name

City, State

IV. CONTACTING YOUR LEGISLATORS

Contacting your members of Congress is easy! Visit www.congress.gov/members to find your members of the U.S. House and Senate and their contact information. Below is a sample email you can use to write your lawmakers and express your concerns with limb loss in America.

SAMPLE GRASSROOTS LETTER

Dear [lawmaker],

As many as 500 Americans lose a limb each day, despite healthcare procedures and innovations that offer clinically effective intervention to save an individual's limb. This is especially true among America's minority populations, which experience amputations at a rate far above their Caucasian counterparts. Alarming trends in amputation rates call for immediate action among policy makers to ensure that no American experiences amputation when their limb could have been spared.

Statistics show that African American, Hispanic American and Native Americans experience limb loss at measurably higher rates because of various factors including greater disease severity and later intervention. Among Medicare beneficiaries, for example, African Americans are four times more likely to experience amputation.

Disease conditions like diabetes and peripheral artery disease (PAD) that lead to amputation are higher among these populations, signaling that more needs to be done to educate these groups of their risks and increase access to limb-salvaging procedures that can also save lives.

Data also show amputees have much higher mortality rates than those whose limbs are spared. In fact, more than 70 percent of amputees will die within three years of their amputation. Therefore, saving a limb can quite literally save a life.

I encourage you to support policy solutions that increase access to limb saving procedures among minority populations to reduce amputations, decrease healthcare spending and dramatically improve lives. We must work together to address the alarming racial limb loss discrepancies in America today so no one is amputated if their limb could have been spared – especially because of the color of their skin.

Thank you for your time and leadership.

Sincerely,

V. SOCIAL MEDIA RESOURCES

Help us spread the word about the Standing TALL campaign online! Organizations and individuals are encouraged to utilize the following resources when sharing information on your social media channels.

HASHTAG

If you are sharing information about Standing TALL on social media, be sure to use our official hashtag, **#TogetherAgainstLimbLoss**.

SAMPLE SOCIAL MEDIA POSTS

Facebook

The Standing TALL campaign seeks to address the unacceptable limb loss disparities in America. Learn more: [LINK] **#TogetherAgainstLimbLoss**

Far too many minority Americans experience limb loss because of vascular disease, which can be easily diagnosed and effectively treated to prevent amputation. No one should experience limb loss unnecessarily! Learn how we are standing **#TogetherAgainstLimbLoss**: [LINK]

African Americans are up to 400% more likely to experience limb loss. Congress must stand **#TogetherAgainstLimbLoss**! Learn more: [LINK]

Twitter

Standing TALL seeks to address the unacceptable limb loss disparities in America. Learn more: [LINK] **#TogetherAgainstLimbLoss**

We are standing TALL **#TogetherAgainstLimbLoss**! Learn how you can get involved: [LINK]

An estimated 500 Americans lose a limb each day. Learn how you can stand **#TogetherAgainstLimbLoss**: [LINK]

African Americans are up to 400% more likely to experience limb loss. Congress must stand **#TogetherAgainstLimbLoss**! [LINK]