

The Phoenix Society for Burn Survivors has been advocating for increased funding for the Burn Injury Model Systems to add 2 additional Burn Injury Model Systems (BMS) sites across the country, update funding to account for inflation, and add additional grant opportunities to address the long-term health needs of burn survivors. The Congressional appropriations bill that passed in 2022 included \$2 million explicitly for NIDILRR to increase the annual funding for SCI and TBI model systems but lacked opportunity for the Burn Injury Model Systems. We are hopeful that when Congress passes its fiscal year 2024 appropriations bill that this additional funding and directive to the National Institute on Disability, Independent Living, and Research Rehabilitation (NIDILLR) will be included.

Over the last 15 years, more than 425,000 people with burn injuries have been discharged into the community in the United States. However, despite an increase in the survival and prevalence of burn survivors and the need for services, resources, and innovative research that address the chronicity of their condition, federal funding for and the number of Burn Model Systems has remained essentially unchanged in its nearly thirty-year existence. **Greater BMS funding is critical to help us understand the needs beyond the acute care setting and begin to address them so those injured do not just survive but thrive after a traumatic injury.** This is more important now than ever, as more patients are surviving severe burn injuries, with a current survival rate of 97%.

Requests for Congress Appropriation Committees:

- Increase the number of Burn Model Systems from 4 to 6 Centers https://msktc.org/burn/model-system-centers. This program is long overdue for a significant increase in the number of centers and with funding that considers inflation and the considerable growth in the burn population since the induction of the BMS \$5.25 Million annually.
- Develop a new **funding opportunity for collaborative work** across BMS sites to address the long-term needs of the population- Disability and Rehabilitation Research Projects Program: Burn Injury Model System (BMS) Centers Collaborative Research Project **\$900,000 annually.**
- Increase funding for the Burn Model System National Data & Statistical Center (BMS-NDSC), https://burndata.washington.edu/, which serves as the premier source of longitudinal burn injury-related statistical data in the United States - \$675,000 annually.
- Increase funding for the Model Systems Knowledge Translation Center (MSKTC), https://msktc.org, the
 MSKTC works with the Phoenix Society for Burn Survivors and the BMS Model Systems on translating
 research and clinical knowledge into resources needed by the community on topics related to burn injury
 that are used globally \$2 Million annually.

We would like to ask you to help the Phoenix Society for Burn Survivors make sure that we let the House and Senate offices know that this is a priority for them to support and they need to weigh in with the Appropriations Committee offices in charge of this process.

This means **reaching out to all seven of the below Appropriations Committee leaders** urging them to support increased funding and language in the House of Representatives and Senate appropriations bill. To do this you can:

- Call their office directly
- Send an e-mail or complete their contact form online

House Representatives:

NOTE: The following representatives only accept online submissions from those who are in their area. Please use the corresponding address listed below for each representative to complete the submission**



Kay Granger (R-TX) <u>-</u> Chair of Appropriations <u>Contact</u> **701 River Run, Fort Worth, TX 76107

Rosa DeLauro (D-CT) - Ranking Member of Appropriations and Subcommittee for Health & Human Services Contact

**Zip code: 06510

Robert Aderholt (R-AL) - Chair of subcommittee that includes Health and Human Services Contact
**205 4th Ave NE, Cullman, AL 35055

Senators:

Patty Murray (D-WA) - Chair of Appropriation Committee Contact

Susan Collins (R-ME) - Vice Chair of the full Committee Contact

Tammy Baldwin (D-WI) - Chair of the Subcommittee that includes Health and Human Services Contact

Shelley Capito (R-WV) – Subcommittee ranking member Contact

Additionally, we ask that you reach out to your states House and Senate members urging them to write or advocate to the appropriations committee members of the House and Senate on this important initiative.

House Members by State: https://www.house.gov/representatives

Senate Members by State: https://www.senate.gov/states/statesmap.htm

Here are some of the talking points we are sharing with advocates:

- Briefly share your connection / expertise / Lived experience related to the needs of this population.
- There is a critical need of increased funding for NIDILRR which grants funding for all competitive grants for the Model Systems including Burn, TBI and Spinal Cord Injury. Clarify, that Burn Model Systems is not a part of National Institute for Health, nor the American Burn Association federal funding.
- The Burn Model System National Database is the premier source of longitudinal data and long-term outcomes research. In addition, it is the only database that collects longitudinal data on pediatric burn survivors.
- Within the past 15 years, the burn survivor population has grown larger than the SCI and TBI populations, yet the Burn Model Systems has 75% less centers.
- Adequate funding that keeps up with inflation is needed to ensure the development and implementation of interventions specific to the burn survivor population is feasible through these grant mechanisms.
- The burn survivor and research community has elicited interest from multiple Congressional offices about the needs of the burn survivor community highlighting the unique expertise and multidisciplinary approach to rehabilitation and program supports that the Burn Injury Model Systems provide.

If you have any questions, please reach out to Amy Acton at Amy@Phoenix-Society.Org

Thank you,

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Amy Acton, Chief Executive Officer