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## “*Living Well*” After Burn Injury: Using Case Reports to Illustrate Significant Contributions From the Burn Model System Research Program

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### Abstract

The Burn Model System (BMS) program of research has been funded since 1993 by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The overarching aim of this program is to improve outcomes and quality of life for people with burns in the areas of health and function, employment, and community living and participation. This review reports on BMS contributions that have affected the lives of individuals with a significant burn injury using case reports to associate BMS contributions with recovery. In January 2020, current BMS grantee researchers assessed peer-reviewed BMS publications from 1994 to 2020. Using case report methodology, contributions were linked to three individuals treated at one of the four Burn Model System institutions. With over 25 years of NIDILRR funding, unique BMS contributions to patient recovery were identified and categorized into one of several domains: treatment, assessment measures, sequelae, peer support, employment, and long-term functional outcomes. A second review for significant results of BMS research that add to the understanding of burn injury, pathophysiology, and recovery research was identified and categorized as injury recovery research. The case study participants featured in this review identified select NIDILRR research contributions as having direct, personal benefit to their recovery. The knowledge generation and clinical innovation that this research program has contributed to our collective understanding of recovery after burn injury is considerable. Using case study methodology with

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three adult burn survivors, we highlight the impact and individual significance of program findings and reinforce the recognition that the value of any clinical research must have relevance to the lives of the study population.

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In 1993, the National Institute on Disability and Rehabilitation Research (NIDRR) within the Department of Education (DOE) initiated funding for the Burn Model System (BMS) program of research, knowledge translation, and dissemination to augment its other model systems for traumatic brain injury and spinal cord injury. With the first competition (1993–1997), three burn centers within the United States were awarded funding: University of Washington (Harborview Medical Center), Seattle, WA; University of Denver Colorado, Denver, CO; and University of Texas Southwestern, Dallas, TX. In 1997, NIDRR increased funding to support a data center and four BMS centers. Since then, they have announced a request for competitive applications every 5 years. Beginning in 2006, NIDRR initiated funding for a Model Systems Knowledge Translation Center (MSKTC) to support all model systems, including the BMS in dissemination and knowledge translation activities. Continued funding for the MSKTC remains in effect today. In 2016, NIDRR transitioned from the DOE to the Health and Human Services (HHS) under the Administration for Community Living (ACL) and was renamed the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). At present, four U.S. burn centers funded under the BMS program by NIDILRR include: University of Washington/Northwest Regional Burn Model System (NWRBMS), Seattle, WA; University of Texas Southwestern/North Texas Burn Rehabilitation Model System (NTBRMS), Dallas, TX; Boston Harvard Burn Injury Model System (BHBIMS), Boston, MA; and University of Texas Medical Branch (UTMB)/Galveston Shriners Hospitals Burn Model System, Galveston, TX. Competitive announcements for 5-year funding cycles have continued with the current funding cycle scheduled to conclude in 2022.

The overarching aim of this federal program is to improve outcomes and quality of life for people with disabilities in the areas of 1) health and function, 2) employment, and 3) community living and participation.

Previous reports by Klein<sup>1</sup> and Amtmann<sup>2</sup> provide details concerning the BMS program, including the procedure for interrogating the BMS Longitudinal National Database by non-BMS researchers. To date, over 125 burn-related manuscripts detailing both single- and multi-center research have been published in both national and international peer-reviewed journals with full or partial NIDRR/NIDILRR funding.

In 2017, a 20-year review of BMS research and related educational materials summarized the most frequently cited BMS articles and quantified the effectiveness of dissemination activities. Twenty-five NIDILRR-supported publications used the BMS longitudinal national database (ie, the multicenter national database repository) detailing psychological and/or functional outcomes, community reintegration, and burn injury characteristics. The authors concluded that the NIDILRR BMS program has played a major role in defining the course of burn recovery, and in making information accessible to the public. They determined that findings from this multicenter BMS database provide an important resource to the burn

community and that the BMS program serves as a good model for collaborative research that is interdisciplinary and outcome-focused.<sup>3</sup>

In this review, we had two aims: 1) to identify significant contributions to the field of burn care from 25 years of NIDILRR funding and 2) to use case study methodology to highlight specific BMS contributions that have had a significant impact for individuals living with a burn injury.

## METHODS

### Review for Contributions

One hundred twenty-five peer-review publications derived from BMS data with NIDRR or NIDILRR funding citation were reviewed for significant contributions in July and December 2019 by six current BMS researchers (G.J.C., N.S.G., K.M., A.E.W., R.K.H., and J.C.S.). Each researcher reviewed their own center publications; researchers from the BMS National Data & Statistical Center (NDSC; authors K.M. and D.A.) reviewed BMS publications authored by external researchers in addition to their own papers; G.J.C. reviewed publications by previous BMS grantees, Johns Hopkins University and the University of Colorado-Denver. If more than one manuscript identified similar findings or outcomes, a general contribution statement was written and all citations referenced. The list of contributions was reviewed and agreed upon by all BMS authors and categorized based on common themes. Each was grouped by these themes and given a domain name. Seven domains were identified as treatment, assessment measures, sequelae, peer support and aftercare, employment, long-term functional outcomes, and injury recovery research (Table 1). Domain names were not predetermined and were derived based on review findings. A final review of the contribution list and domain names in January 2020 included papers scheduled to be published in the 2020 Archives of Physical Medicine and Rehabilitation, a supplement focused on burn rehabilitation.

### Using Case Study Methodology to Highlight Research Significance

Case study methodology allows for the assessment of relevance and significance of research outcomes as they relate to an individual or family. It is a recognized research method that uses an up-close examination of a subject of study (the case) as well as related conditions. Case reports often provide new ideas for research and discovery and add to our understanding the natural history of a disease.<sup>4,5</sup> Merriam-Webster defines case study as “an intensive analysis of an individual unit (such as a person or community) stressing developmental factors in relation to environment.”<sup>6</sup> Authors from the NWRBMS, BHBIMS, and NTBIMS invited an individual treated at their center to participate in this review and to collaborate as a coauthor. Each adult burn survivor was asked to review the list of contributions (Table 2) for findings that had an impact on their own recovery and rehabilitation. For these collaborators, we asked each to provide information about their injury and current situation. This information formed the basis for each of the case studies presented.

## RESULTS

The review authors identified 40 unique (ie, not overlapping) and significant contributions to patient recovery from the 125 publications reviewed. Contributions were grouped based on similarity and seven different domains identified. The following information provides a description of each domain with the table providing a summary of the contributions with citations.

### Treatment

Key findings within this domain include both acute and longer-term treatment modalities. Each therapy or treatment identified seeks to minimize common injury sequelae such as acute pain, a heightened metabolic response, limited range of motion, and long-term hypertrophic scarring. Research concerning exercise programming focused on benefits to include prevention of common sequelae and the physical, mental health, and psychosocial outcomes of exercise after burn injury.

### Assessment Measures

Findings from studies that developed or validated new or existing assessment measures, predominately focused on the social impact of injury, evaluation for heterotopic ossification (HO) risk, community reintegration, and postburn itching, were highlighted in this domain. Both burn-specific and generic measures were included.

### Sequelae

Reports on common sequelae identified using both the longitudinal national database and single-center research were included in this domain. Contributions focused on issues that had impact on quality of life, to include physical sequelae (itch, fatigue, sleep disturbance), cognitive deficits (measured by total cognitive Functional Independence Measure or FIM scores), psychosocial issues (depression), and physical limitations (related to neuropathy, hypertrophic scar, and/or joint and skin contractures).

### Peer Support and Aftercare

Contributions detailing the value of peer support and use of telemedicine during aftercare were included in this domain.

### Employment

Longstanding NIDILRR funded efforts to understand employment and return to work after burn injury as surrogates for community integration date back to 2001 with the most recent published in January, 2020. Barriers to returning to work (RTW), factors affecting employment, and evaluation of interventions aimed to assist with RTW are included in this domain.

## Long-Term Functional Outcomes

Both modifiable and nonmodifiable factors related to less than optimal, long-term functional outcomes and health-related quality of life issues were identified and included in this domain.

## Injury Recovery Research

This domain highlights multiple papers that describe the validation of the Fibroproliferative Red Duroc Porcine Model. In addition, a paper that details research-related study actions to increase retention and data collection long term was included.

## CASE STUDY REPORTS

The following case studies portray three individuals treated at one of the three BMS burn centers [UW Medicine Regional Burn Center; Sumner Redstone Burn Center at Massachusetts General Hospital and Spaulding Rehabilitation Hospital; Parkland Hospital and University of Texas (UT) Southwestern]. All information was provided by the individual and/or confirmed by hospital medical record review.

### Chris Madison

On November 20, 2015 at the age of 27, Chris sustained a 70% Total Body Surface Area (TBSA) burn from a gas explosion while working on heavy equipment that his family owned in Kotzebue, Alaska (Figure 1). At the time of his injury, Chris was married with two young children. Initial field assessments determined that Chris would require specialized burn care because of the extent of his burn injury, estimated depth (most of his injuries were full-thickness/third degree), and some with circumferential areas of injury on all four extremities. He was flown to Anchorage, Alaska where escharotomies were performed on his extremities. He was ultimately air-evacuated to Harborview Medical Center (HMC), home to the University of Washington (UW) Medicine Regional Burn Center, and the Northwest Regional Burn Model System (NWRBMS) for definitive care. He underwent nine operative procedures with over 57% of his body requiring autografting to his face, arms, chest, back, and legs. Due to an inhalation injury sustained during the explosion, Chris was intubated and ventilated for a total of 18 days. Over 2,000 miles from home, Chris spent the next 62 days at HMC (46 in the Burn Intensive Care Unit and 10 days in the HMC inpatient rehabilitation unit), with wife Ashley at his side.

Today, Chris considers himself to have made a full recovery, having returned home to Kotzebue and work. He enjoys pursuing outdoor activities with his family, which has grown with the addition of his third child in 2019. Chris credits Ashley for her role in helping him achieve a full recovery and offered the following comments about how the BMS research affected him personally:

### TREATMENT

- “I did experience a noticeable reduction in burn scar hypertrophy when I wore the pressure garments for extended periods.”—referencing the clinical benefits of custom-fit pressure garments.<sup>7</sup>

## ASSESSMENT MEASURES

- “These [survey questions]<sup>Ψ</sup> helped greatly with addressing issues I had not prepared for posthospitalization.”—concerning the use of the Community Integration Questionnaire used in our BMS longitudinal research study.<sup>16</sup>

## SEQUELAE

- “Perineum burn contractures and surgical release resulted in longer hospital stay. Emphasis on scar tissue massage and stretching helped with long-term healing and combatting further contractures. Knowledgeable [physical and occupational] therapists prepared me for my at-home regimen.”—in reference to contracture severity and large burn size.<sup>30,31</sup>

## PEER SUPPORT AND AFTERCARE

- “While I did not join an actual support group, I did read about other burn survivor stories on social media. This helped with not only my social interactions, but also to know that the associated mental trauma was normal with the injury and healing.”—in reference to the finding that peer support improves social interaction.<sup>38</sup>
- “Telemedicine sessions with HMC saved me \$1,000 round trip flights from rural Alaska.”—referencing the cost reductions associated with telemedicine.<sup>40</sup>

## EMPLOYMENT

- “The neuropathic pain and itching did affect my ability to sleep soundly, which did negatively impact my sleep schedule. For me, this was the second major factor with RTW [return to work]”—in reference to the finding that returning to work is negatively affected by sleep disturbance and chronic pain.<sup>41</sup>

## LONG-TERM FUNCTIONAL OUTCOMES

- “I think meeting all of these criteria provided me an incentive to get through rehab quicker and to get back to my work, family, and former hobbies.”—concerning the finding that survivors who are young, married, employed and higher functioning at time of admission to inpatient rehabilitation demonstrate best outcomes.<sup>48</sup>

### Diana Tenney

On March 7, 2010 at the age of 54, Diana sustained a 94% TBSA burn while using gasoline as an accelerant when burning tree limbs in her back yard (Figure 2). At the time of the incident, she was living with her fiancé in their single family home. Diana was initially cared for at a local hospital in New Bedford, Massachusetts before her transfer to Massachusetts General Hospital (MGH) in Boston, MA. At MGH she was re-assessed and the majority of her injuries were determined to be full-thickness with only 4% partial-thickness burns to the center of her face. Diana was admitted to the Sumner Redstone Burn Center at MGH where she spent the next 6 months with her fiancé, Jerry at her side. During her initial hospitalization, she underwent over 100 procedures under anesthesia. She was then

transferred to Spaulding Rehabilitation Hospital (SRH) where she spent the next 7 months. While at SRH, Diana underwent surgery on both elbows for HO and participated in therapy to help her regain 98% full range of motion. After her discharge from SRH on April 11, 2011, she underwent approximately 30 additional reconstructive procedures including scar tissue removal from her left cornea. In October of 2015, Diana was admitted to the hospital due to a wound infection. In addition to the infection, she had stomach viral-like symptoms, including uncontrollable chills. She was in the hospital for 9 days and diagnosed with Henoch-Schonlein Purpura with blisters from her knees to the bottom of her feet. During this hospital stay, Diana developed fistulas in her submandibular salivary glands and underwent removal of those in 2016 and 2017.

Despite many physical issues, Diana considers herself guardedly in acceptable physical health. Pain is usually muscular and neurological in nature but she remains physically active. Although she never returned to her paid career in outside sales, she has made a full-time effort to help other burn survivors in their recovery through peer support. She is the President of the Burn Survivors of New England, Co-Director of the Wellness Program at Phoenix World Burn Congress, Co-Director of Knowledge Translation at the Boston Harvard Burn Injury Model System and is actively building bridges with other organizations for advocacy and awareness. Diana was featured in the 2017 video, “Exercise after Burn Injury” that highlights the benefits of exercise after experiencing a burn injury (<https://msktc.org/burn/Hot-Topics/Exercise/Exercise-After-Burn-Injury>). She also assists two home-based businesses with office administration, scheduling, website design and maintenance, and book-keeping.

Diana’s experience with the BMS is that the research is “useful in her postburn recovery, providing a sense of community and collaboration.” She also expressed that BMS leadership listens and reacts to the real needs that recovering burn survivors face, many of which have affected her personally. Diana offered the following comments regarding the BMS research:

### **TREATMENT**

- “Not only did community-based group exercise help with my mobility and healing, it helped me to return to a social life outside of the burn community.”—concerning the physical and emotional benefits of exercise after injury.<sup>13</sup>

### **ASSESSMENT MEASURES**

- “By participating in the LIBRE instrument process, starting with the Burn Survivors of New England focus group, it helped me immensely in my social recovery and reintegration. Although I thought I was fully participating in postburn life, it brought awareness that some areas needed more attention, effort and resolution.”—referencing the development and use of the Life Impact Burn Recovery Evaluation Profile to study the social recovery of burn survivors.<sup>21</sup>
- “In general, I continue to benefit by applicable assessment measures although I was not in the population at the time of the study(s). They not only help me to understand more about my burn injury, but assist in understanding and explaining to other burn survivors factors/solutions to their injury during peer

support efforts.”—in reference to the many Patient-reported Outcome Measures (PROMs) used by the BMS research program.<sup>2,15,16,19,53</sup>

### SEQUELAE

- “Most of the research on sequelae is applicable in my postburn life because of the size and severity of my burn injury and lengthy hospitalizations with many complications including HO, contractures, hypertrophic scarring, renal failure and diagnosed sinus tachycardia.”—in reference to several studies addressing the impact and significance of postburn sequelae and complications.<sup>17,29,31,34</sup>

### PEER SUPPORT AND AFTERCARE

- “Peer Support, in conjunction with enthusiastic medical community support has been the most influential factor in my burn recovery. Continuing conversations with burn specialists and other survivors in the New England burn community improves and enlightens.”—referencing literature identifying the benefits of peer support.<sup>38</sup>
- “I believe my involvement with Peer Support has shown in my scores on the LIBRE Profile.”—indicating peer support has had a positive effect on her social recovery as evidenced by her LIBRE Profile scores.<sup>39</sup>

### EMPLOYMENT

- “Due to the length of my post-burn recovery and advanced age, I was not able to go back to work and chose to instead become very active in all aspects of burn recovery and the burn community.”—regarding difficulties returning to work post-burn injury which is a focus for several BMS research studies.<sup>42,43,46</sup>

### LONG-TERM FUNCTIONAL OUTCOMES

- “Surviving as an older adult presents its own challenges with cognition, memory and physical challenges. The burn certainly didn’t help with regular issues of aging, but it reinforces the necessity of physical activity and my post-burn work enhances cognitive skills.”—referencing how experiencing a burn injury at age 54 has affected her long-term outcomes.<sup>53</sup>

### Joe Yeakley

On January 17, 2014, Joe—a volunteer firefighter and his team were battling a house fire in Lindale, TX when it collapsed on him. Initial field assessments determined that Joe would require specialized burn care and he was airlifted from the scene to Parkland Memorial Hospital/UT Southwestern in Dallas, TX (Figure 3). Joe was intubated in the field and initial assessments at Parkland determined that he had sustained a 55% Total Body Surface Area (TBSA) burn—much of which was third- and fourth-degree injuries. For the next 156 days, Joe was cared for at Parkland Hospital and UT Southwestern (96 days in the Burn Intensive Care Unit at Parkland, 60 days in inpatient rehabilitation at UT Southwestern, and 105 days of ventilation that required tracheostomy placement). During his initial hospitalization, Joe underwent 13 operative procedures with autografting to his



face, chest, abdomen, shoulders, back, bilateral upper arms, forearms, hands, digits, and bilateral legs. He required amputation of all his fingers as well as some contracture releases.

At the time of his injury, Joe (51 years old) and his wife, Denise had just celebrated the marriage of their daughter. Denise stayed by his side throughout his hospitalization and recovery. Today, despite some lifestyle adjustments due to his injury, Joe considers himself “blessed.” He says he had an amazing medical team and received excellent medical care. In addition, Joe believes that he was “very blessed that Denise was very good at researching ways to make my life better and more independent.” Due to the support from the Parkland/UT Southwestern staff and his family, Joe has been able to remain physically active. He does so by attending group personal training sessions throughout the week and pacing himself when mowing his 2-acre yard. When his work allows, Joe participates in the Parkland Peer Support Group and often spends time visiting with patients in the burn unit. Today, Joe is home and back at the fire station. He spends his time with family, working out, and teaching classes at a local junior college and at Texas A&M University. Joe provided the following comments about how the BMS research affected him:

### TREATMENT

- “I loved paraffin...I would get it 2–3 days a week on my arms.”—referring to a type of therapy in which paraffin wax is applied to areas of healed skin before range of motion and other therapeutic exercises commence.<sup>14</sup>
- “Gary [fellow firefighter and burn survivor] would set a timer and make us go all the way up and then come all the way down the stairs.”—referring to physical therapy sessions that when together, they pushed each other to work harder.<sup>13</sup>

### ASSESSMENT MEASURES

- “It’s a good way to see your progress from the beginning to now...I couldn’t answer that question last time.’—referring to the BMS questionnaires administered.<sup>2</sup>
- “Some of the questions help you think I might need to look out for this later on.”—referring to how the BMS study questionnaires are structured.<sup>2</sup>
- “There were so many NO’s before, now there are only a few.”—referring to the progress made on each BMS questionnaire from time of injury to present day.<sup>2</sup>
- “Heterotopic Ossification was found in my shoulder during inpatient rehab” —referring to the research concerning heterotopic ossification and risk assessment.<sup>17</sup>

### SEQUELAE

- “I have foot drop in my left foot. I was burned down to the bone on my left knee and if I’m not paying attention I can stumble and fall. When I go to the gym I wear a dorsi-strap.’—referring to the neuropathy in his left lower extremity.<sup>32</sup>
- “I wasn’t receiving medication before my accident and I was determined to get off all medications when I got home. Dr. Kowalske said I would need to

slowly wean off it.’—referring to the depression he developed after injury and medications he was prescribed for treatment.<sup>35,36</sup>

- “I remember having fingers because I looked down and had pins in them. I can still pick things up and I can sign my name with both hands or I have a pen holder that I can wear to write.”—referring to the amputation of all his digits on both hands and using the web space between where his thumb and index finger were on his left hand.<sup>33</sup>
- “I had weekly measurements for extension.”—referring to how some patients develop contractures at time of discharge from the hospital.<sup>34</sup>

### PEER SUPPORT AND AFTERCARE

- “Peer support offers you hope and inspiration; you can see where you are now and where you can be. It helps you understand you’re not the only one; you can get through this.’—referring to new survivors going to peer support group meetings and seeing survivors with older injuries and farther into their recovery.<sup>38</sup>
- The “first support group I went to Dr. Arnoldo did a presentation on *Burn Survivors and Surviving the Heat*. When I mow [the lawn], I do the front yard then I go sit in my chair in the garage in front of a fan. I have a [refrigerator] with water and Gatorade® to stay hydrated... we have sunscreen in all the cars.”—referring to how going to the peer support group was informative and beneficial.<sup>38,39</sup>
- “Its not just about the survivor”—referring to how his daughter saw a gap in (Survivors Offering After Recovery) SOAR where there was material for spouses and young children but not for adult children.

### EMPLOYMENT

- “I was originally a chaplain but then was asked to be fire chief”—referring to the finding that pre-burn employment status is the strongest predictor for postburn employment and returning to work.<sup>44</sup>
- “I still go out on calls”—which challenges the finding that that working-age adults with burn-related amputations are less likely to be employed at 12-months postburn.<sup>47</sup>
- “I can connect my computer equipment by myself.”—referring to how the will to be independent enables him to complete work assignments when traveling.

### LONG-TERM FUNCTIONAL OUTCOMES

- “Before my burn I worked out with a personal trainer and ran every day; the surgeons told my wife when she got to the hospital [the] key to surviving is good physical health before the injury”—referring to how functioning at a higher level prior to injury demonstrates better outcomes.<sup>48</sup>

- “We make it [my burn anniversary] into a celebration instead of a sad day”—referring to how satisfaction with life after burn is consistently lower than that of non-burn norms and how he challenges that research finding.<sup>53</sup>

## DISCUSSION

The aim of our review was twofold: 1) to identify significant research findings (ie, contributions) from a review of 125 BMS peer-reviewed publications, and 2) to examine the value of these contributions (if any) to individuals with burn injury. Forty unique contributions were identified by BMS researchers; of these, 25 contributions (63%) were selected by at least one individual from our case study reviews. These 25 contributions were derived from 27 publications and categorized within six domains: treatment, assessment measures, sequelae, peer support and aftercare, employment, and long-term functional outcomes. When analyzing survivor comments from the case studies, we found that many overlapped with predominant themes that addressed social integration after injury, value of peer support, and the impact of wound/skin contractures and HO. Noteworthy is that some of the survivor comments challenged our research findings, noting their experience differed from the research outcomes we identified. This is to be expected as research findings represent the majority, and not necessarily that of an individual’s experience. Our findings provide support for continued research in these areas of recovery and the value of including key stakeholders as research collaborators. Furthermore, this publication provides a means to disseminate BMS contributions that have been recognized as clinically impactful.

None of the selected contributions mapped to the *Injury Recovery Research* domain received a survivor comment. It may be that this domain does not lend itself to case study reporting and evaluation due to the nonclinical aspect of the findings. Whereas patients and their families may value the potential of a preclinical animal model for testing novel interventions, a more appropriate metric of the success of this funding effort might be adoption of the model by other researchers.<sup>61</sup> Penetrance can also be quantified by the number of publications by non-BMS investigators who have confirmed the abnormal gross and histological appearance of scars created on the Red Duroc pig,<sup>62</sup> thus providing further evidence of this model’s use in research.<sup>63,64</sup>

By using case study reporting, we have illustrated the personal impact that our research has had on individuals and their families. This report reinforces the BMS commitment to patient engagement in our research efforts. Engaging patients in biomedical research, commonly referred to as patient-centered outcomes research (PCOR), emerged from the practice of engaging patients as partners and advisors in biomedical research. The goal of which is to generate more useful evidence and treatments that improve health outcomes. By engaging patients in the entire research process, clinical research is more likely to generate useful evidence that will inform health decisions.<sup>65</sup> A 2017 publication summarizing timely themes for the next 10 years of burn rehabilitation research<sup>66</sup> specifically pinpointed “integrating burn survivors into rehabilitation research” which is a concept that NIDILRR and others (eg, PCORI) have long required of their grantees.

Lastly, this report corroborates prior publications that have enumerated<sup>1,2,67</sup> BMS program contributions<sup>3</sup> to underscore the value of this federal program. Collectively, the NIDILRR-funded Burn Model System program has advanced the burn community's appreciation for recovery after injury and the importance of understanding long-term outcomes. In spite of growing recognition that assessment of outcomes after a traumatic injury must include more than mortality<sup>68,69</sup> and disposition, few funding opportunities supporting long-term assessment after injury exist.

## LIMITATIONS

Defining factors for what constitutes a significant contribution were not defined a priori, but were at the discretion of each BMS reviewer. However, we chose this inclusive approach to maximize the variety of BMS data that the stakeholders could consider in their assessment of clinically impactful findings. One other limitation of this review of BMS contributions to patient recovery is that we limited our assessment to BMS peer-reviewed publications. As such we did not include the significant commitment to dissemination and knowledge translation, including BMS factsheets, webinars, or videos. These BMS resources, many available in Spanish,<sup>70</sup> can be accessed online at the Model System Knowledge Translation Center (MSKTC) website (<https://msktc.org>). Finally, the individuals affected by a burn injury who were invited to provide feedback about the impact of BMS research on their recovery are adults; parents of young survivors as well as pediatric survivors themselves may have a different perspective, one which deserves attention.

## CONCLUSIONS

The knowledge acquisition and clinical innovation that the Burn Model System program has contributed to our understanding of recovery after burn injury is considerable. Case study highlights from three adult survivors illustrate the impact of these findings on an individual level. We believe that partnering with burn survivors in the development of this review has shifted our project from a traditional, investigator-driven report to one that collaborates with key stakeholders. Ultimately, the value and importance of any clinical research must have relevance to the lives of the study population. Our collective observations support the NIDILRR-funded Burn Model System as an integrated, longitudinal patient-centered research model.<sup>3</sup>

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**Figure 1.**  
Christopher Madison.



**Figure 2.**  
Diana Tenney.



**Figure 3.**  
Joseph Yeakley.

**Table 1.**

Study domains

Domain name	Publication elements
Treatment	Preventive or treatment modalities for common postburn sequelae are discussed
Assessment Measures	New or existing assessment measures are developed and/or validated for the burn-injured population; could address either burn-specific or generic measures
Sequelae	Reports that include discussion of any common postburn sequelae
Peer Support and Aftercare	Reports that address either peer support and/or aftercare
Employment	Reports that address postburn employment and/or return to work
Long-term Functional Outcomes	Reports concerning functional outcome(s) following acute hospitalization; no limitation on time since injury
Injury Recovery Research	Reports that address burn injury research models or activities

**Table 2.**

Significant BMS contributions (publication date range 1994-January 2020)

Domains	Significant contributions with attribution
Treatment	<ul style="list-style-type: none"> <li>• Custom-fit pressure garments are helpful for people with moderate to severe postburn scarring<sup>7</sup></li> <li>• Immersive virtual reality reduces pain during active range of motion (ROM) exercises<sup>8</sup></li> <li>• Transcranial direct current stimulation (tDCS) found ineffective for postburn itch<sup>9</sup></li> <li>• β-blockers minimize postburn metabolic response and modulate cutaneous response to injury<sup>10</sup></li> <li>• Oxandrolone/Propofol (OxProp) improves scarring and psychosocial outcomes in pediatric burn survivors<sup>11</sup></li> <li>• A community-based exercise program effective for severely burn-injured children<sup>12</sup> and adults<sup>13</sup></li> <li>• Sustained stretching with paraffin is a valuable adjunct for improving shoulder range of motion after burn injury<sup>14</sup></li> </ul>
Assessment measures	<ul style="list-style-type: none"> <li>• Perceived Stigmatization Questionnaire (PSQ), Social Comfort Questionnaire (SCQ),<sup>15</sup> and Community Integration Questionnaire-13<sup>16</sup> validated in burn survivors</li> <li>• Heterotopic Ossification risk-assessment scale developed<sup>17</sup></li> <li>• Young Adult Burn Outcomes Questionnaire (YABOQ) developed<sup>18</sup></li> <li>• The 5-D Itch Scale and Satisfaction With Life Scale (SWLS) validated with burn survivors and psychometrics improved<sup>19,20</sup></li> <li>• Life Impact Burn Recovery Evaluation (LIBRE) that assesses social participation developed in collaboration with The Phoenix Society for Burn Survivors<sup>21</sup></li> </ul>
Sequelae	<ul style="list-style-type: none"> <li>• Two-year prevalence estimated for postburn itch in pediatric burn survivors<sup>22</sup></li> <li>• Long-term prevalence estimated for postburn itch, fatigue, depression, sleep problems, neuropathy in adult burn survivors<sup>23-26</sup></li> <li>• Lower health-related quality of life (QoL) after major burn injury, similar to traumatic brain injury (TBI)<sup>27</sup></li> <li>• 25% of burn survivors have cognitive deficits at time of discharge from inpatient rehabilitation<sup>28</sup></li> <li>• Inpatient complications (UTI, VTE, pulmonary, and renal failure) associated with lower long-term QoL<sup>29</sup></li> <li>• Heterotopic Ossification associated with elbow flexion contractures and time to wound closure over major joints<sup>17</sup></li> <li>• Larger burn size and longer hospital length of stay associated with more severe contractures; early intervention is essential<sup>30,31</sup></li> <li>• Good prognosis for burn-related mononeuropathy<sup>32</sup></li> <li>• Positive outcomes (modified grasp, ADL independence) identified following significant and severe hand burns<sup>33</sup></li> <li>• Most joint contractures are mild to moderate in severity; 1/3 of patients have at least 1 contracture at time of hospital discharge<sup>34</sup></li> <li>• Routine outpatient screening for depression is important<sup>35-37</sup></li> </ul>
Peer support and aftercare	<ul style="list-style-type: none"> <li>• Peer support for adult burn survivors improves social interaction<sup>38</sup></li> <li>• Adult burn survivors who attended peer support scored better in 3 LIBRE Profile scales: Social interaction, Social activities, and Work and employment<sup>39</sup></li> <li>• Telemedicine between burn center and rehabilitation hospital streamlined patient care and reduced healthcare costs while maintaining quality of care and patient satisfaction<sup>40</sup></li> </ul>
Employment	<ul style="list-style-type: none"> <li>• Return to Work (RTW) is less likely for those with sleep disturbance and chronic pain<sup>41</sup></li> <li>• Preburn employment status is the strongest predictor for postburn employment and RTW<sup>42-44</sup></li> <li>• Intervention bundle leads to greater RTW for those with Workers' Compensation insurance coverage in Washington State<sup>45</sup></li> <li>• Common barriers to RTW identified for those working prior to injury<sup>43,46</sup></li> <li>• Early (physical) and late (psychosocial and environmental) barriers to RTW identified for those working prior to injury<sup>46</sup></li> <li>• Less likely to be employed 12-month postburn: working-age adults with burn-related amputation,<sup>44,47</sup> older individuals,<sup>44</sup> females,<sup>44</sup> those with long, acute hospitalizations,<sup>44</sup> and those with high pain interference at hospital discharge<sup>44</sup></li> <li>• Inpatient rehabilitation settings (vs skilled nursing facilities) associated with greater likelihood of employment at 1 year<sup>48,49</sup></li> <li>• Adults with work-related burns report worse scores on the LIBRE Work and Employment scales<sup>50</sup></li> </ul>
Long-term functional outcomes	<ul style="list-style-type: none"> <li>• Cognition after burn injury worse than other non-neurological injury populations in the inpatient rehabilitation settings<sup>51</sup></li> <li>• Survivors who are young, married, employed, and higher functioning at time of admission to inpatient rehabilitation demonstrate best outcomes<sup>48,52</sup></li> <li>• Older age, worse mental health, and preburn unemployment related to dissatisfaction with life which progressively gets worse<sup>53</sup></li> <li>• Satisfaction with life after burn is consistently lower than that of nonburn norms<sup>53</sup></li> </ul>

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**Significant contributions with attribution**

- The Fibroproliferative Red Duroc Porcine Model validated as a large animal model for burn wound research<sup>54-59</sup>
- Best practices identified for longitudinal burn outcomes research<sup>60</sup>

**Domains**

Injury recovery research

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