The Burn Model System Centers Program

A project funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), A Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS)

BURN MODEL SYSTEM
BMS
ADVANCING RECOVERY THROUGH KNOWLEDGE

NIDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research

MSKTC
SCI · TBI · BURN
Model Systems Knowledge Translation Center

Project Design

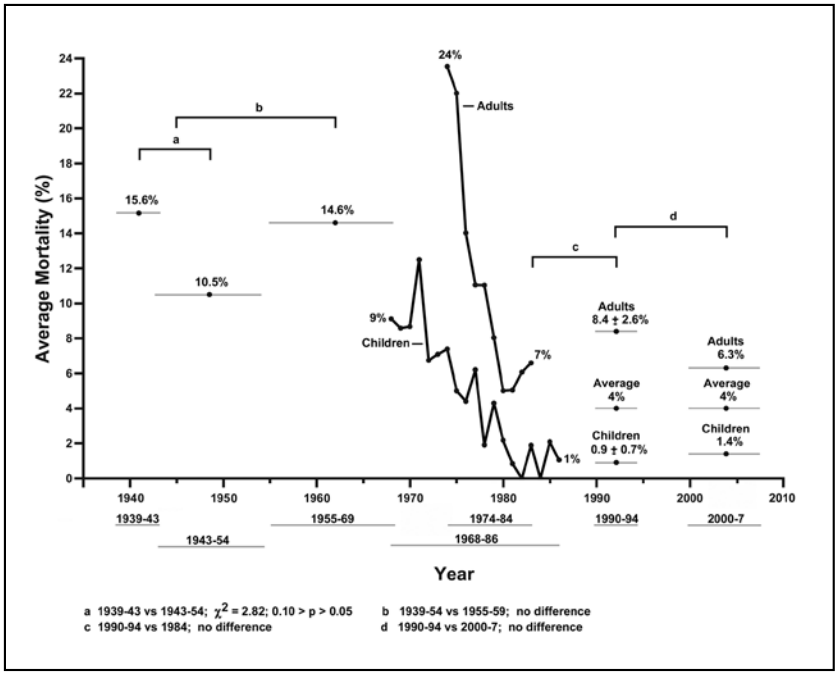
- A unique prospective, longitudinal multi-center study
- Examines health, employment, and community reintegration outcomes post-burn injury
- Consists of the BMS National Longitudinal Database as well as site-specific and collaborative projects

Burn Model System (BMS) Program Design

- One of three multi-center programs sponsored by NIDILRR to examine outcomes following the delivery of a coordinated system of acute trauma care and rehabilitation:
  - Burn Injury Model System (begun 1994)
  - Traumatic Brain Injury Model System (begun 1987)
  - Spinal Cord Injury Model System (begun 1970)
- Examines the course of recovery and the health, employment, and community reintegration outcomes after burn injury
- Consists of:
  - Prospective, longitudinal national database
  - Site-specific research projects
  - Multi-center research and knowledge translation projects

Increase in Survival

Advances in acute burn care have significantly reduced mortality and increased the number of people living with severe burn injury.

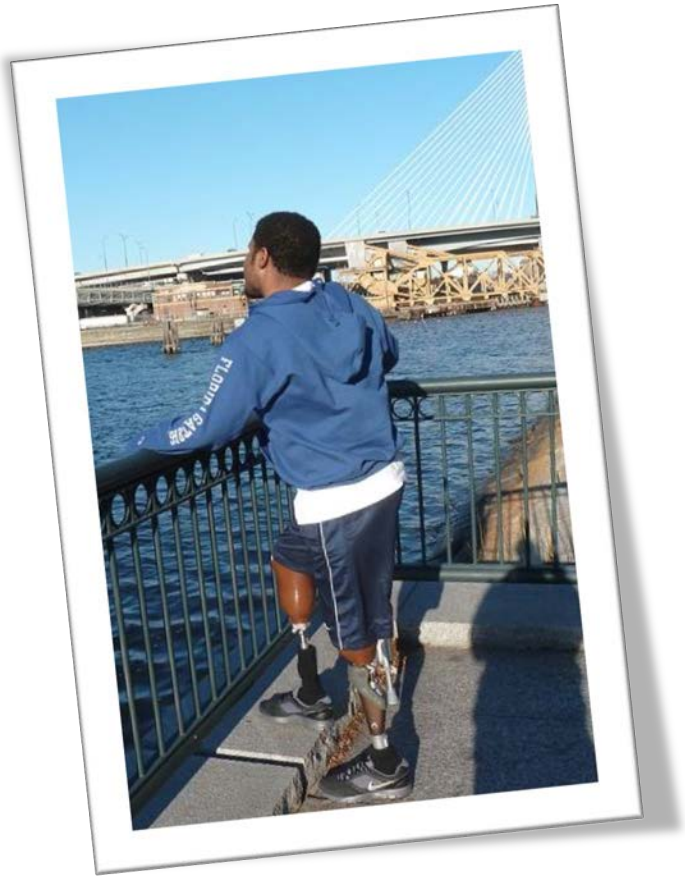


Tompkins RG. Survival from Burns in the New Millennium: 70 Years Experience from a Single Institution. *Annals of Surgery*. 2015;261(2):263-268.

As a result of major decreases in mortality, the field of burn care has transformed and is increasingly focused on improving the **quality of life and long term outcomes** of burn survivors.

Long-term Outcomes

- The BMS is the only multi-center, research program dedicated to advancing the long-term recovery of burn survivors.
- Aspects of recovery:
  - Physical
  - Psychological
  - Social
  - Vocational



What makes up the BMS?

- "Model" Multidisciplinary Care Centers
- A longitudinal national burn outcomes database
- Site-specific, targeted research projects
- Collaborative "module" projects
- Knowledge dissemination
- Collaboration

Currently funded BMS Centers

- Boston-Harvard Burn Injury Model System in Boston, MA (PI: Jeffrey Schneider, MD)
- University of Texas Medical Branch/Shriner's Burn Injury Model System in Galveston, TX (PI: David Herndon, MD)
- North Texas Burn Rehabilitation Model System in Dallas, TX (PI: Karen Kowalske, MD)
- Northwest Regional Burn Model System in Seattle, WA (PI: Nicole Gibran, MD)
- National Data and Statistical Center at the University of Washington in Seattle, WA (PI: Dagmar Amtmann, PhD)

Previously funded BMS Centers

- Johns Hopkins Burn Model System in Baltimore, MD (PI: Jim Fauerbach, PhD) (1997-2012)
- National Data and Statistical Center at the University of Colorado in Denver, CO (PI: Dennis Lezotte, PhD) (1994-2012)
- University of Colorado in Denver, CO (1994-1997)

Requirements of BMS Centers

- Clinical care
  - BMS Centers must be associated with a health care organization that provides a multidisciplinary system of rehabilitation care specifically designed to meet the needs of individuals with burn injury, including but not limited to physical, psychological, and community reintegration needs, encompassing a continuum of care, including emergency medical services, acute care services, acute medical rehabilitation services, and post-acute services

Requirements of BMS Centers (cont.)

- Knowledge translation
  - Collaborate with the NIDILRR-funded Model Systems Knowledge Translation Center (MSKTC) to provide scientific results and information to stakeholders
  - Collaborate with external organizations such as the American Burn Association and the Phoenix Society

Requirements of BMS Centers (cont.)

- Knowledge generation
  - Enroll at least 30 participants per year into the BMS longitudinal database
  - Collect follow-up data on all participants at 6 months, 1 year, 2 years, and every 5 years post injury
  - Propose and conduct 1-2 site-specific research projects
  - Participate in at least one module project

BMS National Data & Statistical Center: Funding priorities 2018-2023

- Maintain the BMS National Longitudinal database
  - Enhance the ability of the BMS to securely collect and store high quality and reliable data
  - Promote inclusion of participants of all racial and ethnic backgrounds
  - Ensure that BMS data is easily available to and usable by researchers
- Conduct rigorous research on and disseminate outcomes utilizing the BMS NDB
- Collaborate across Model Systems and outside organizations
- Provide training, technical assistance, and evaluation

BMS National Longitudinal Database Objectives

- Contributes to improved care and outcomes of individuals (adult and pediatric) with severe burns
- Contributes to evidence-based rehabilitation interventions and clinical and practice guidelines that improve the lives of individuals with severe burns
- Studies the longitudinal course of severe burn injuries and their secondary effects and factors that affect that course
- Identifies and evaluates trends over time in etiology, demographics, injury severity characteristics, treatment of burns, health services delivery, and short-term and long-term outcomes of persons with severe burns
- Establishes expected rehabilitation outcomes for persons with severe burns
- Facilitates other research by identifying potential research participants for enrollment in burns clinical trials and other research projects or as a springboard to population-based studies

Participant Inclusion Criteria

Enrollment at discharge of participants meeting the following criteria:

- Burn injury requiring surgery for wound closure prior to hospital discharge:
  - 0-65 years of age: ≥20% total body surface area burned (TBSA); or,
  - ≥65 years of age: ≥10% TBSA
- OR, burn injury of any age or size requiring pre-discharge surgery for wound closure when the burn includes:
  - Hand burn and/or face burn and/or feet burn
  - Surgery does not have to occur on the critical area affected (hand/face/feet)

Inclusion Criteria, 2 of 3

- Surgery for closure of burn wound must occur within 30 days of burn injury
  - Autografting is considered wound closure; those patients that have only xenografting or allografting are not eligible
- Eligible burn injury etiologies:
  - Fire/flame, scald, contact with hot object, grease, tar chemical, hydrofluoric acid, electricity (low/high voltage or lightning), radiation, UV light, flash burn, and other burn (road rash, abrasions, steam burns, etc.)

BMS Inclusion Criteria, 3 of 3

- Received primary treatment in the Burn Injury Model System Center from the time of burn (outpatient or inpatient) for primary burn wound closure
- In addition to acute care, will be provided comprehensive rehabilitation services at the Burn Injury Model System Center, including:
  - Physiatric, physical, occupational, recreational, psychological, vocational, or other traditional rehabilitation therapies
- Informed consent signed by burn survivor or guardian

How the BMS collects data for the National Longitudinal Database

Longitudinal data collection from participants at regular intervals after burn injury

- Form I: Acute hospitalization discharge
  - Administered via in-person interview, telephone interview, or mailed questionnaire
  - Pre-burn and injury information collected
  - Injury information, demographics, and pre-burn and discharge measures of physical and mental health (VR-12 and NIH Toolbox measures), participation, satisfaction with life, pain, etc.

BMS National Longitudinal Database Data Collection

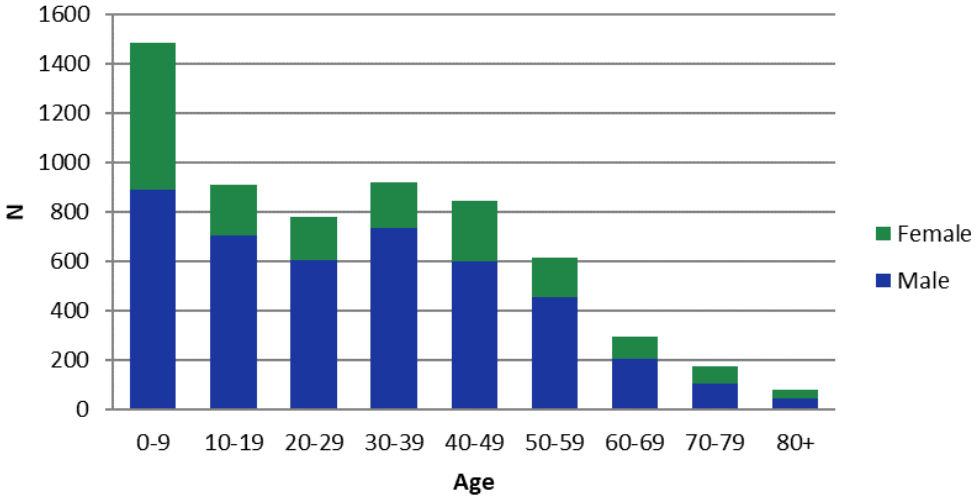
- Form II: Follow-up conducted at 6 months, 1 year, 2 years, and every 5 years thereafter
  - Administered via in-person interview, telephone interview, or mailed questionnaire
  - Includes follow up injury information, return to work/school, and measures of physical and mental health (VR-12, PROMIS), participation, satisfaction with life, PTSD, depression, and anxiety

BMS Database Participants by Age & Gender, 1993-2017

Table 1. Number of Cases by Gender

Gender	Number of Cases	%
Male	4,339	71.1
Female	1,761	28.9

Figure 1. Age and Gender



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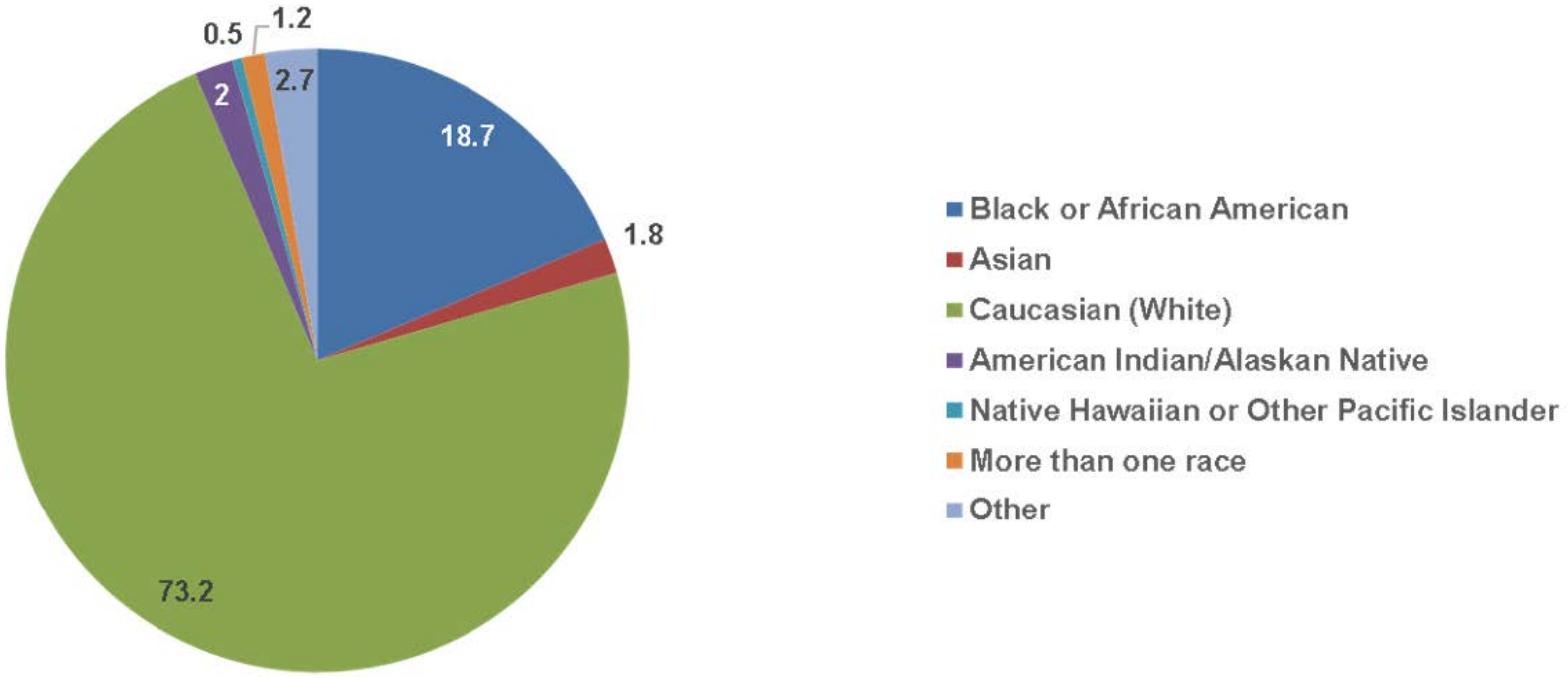
Race of BMS Database Participants, 1994-2017

Figure 2. Distribution of Participants by Race



Cause of Injury, 1994-2017

Table 2. Number of Cases by Cause of Injury

Cause of Injury	Number of Cases	%
Fire/flame	3,564	58.4
Scald	978	16.0
Grease	448	7.3
Electricity	375	6.2
Contact with hot object	255	4.2
Flash burn	168	2.9
Chemical	98	1.6
Tar	60	1.0
Other	29	0.5
	Total: 5,975	

Employment and School Status after Burn Injury

Table 3. Employment Status After Burn Injury, Participants 18 – 65 Years of Age

	6 Months		12 Months		24 Months	
Employment Status After Burn Injury, Participants 18 - 65	Number of Cases	%	Number of Cases	%	Number of Cases	%
Working	1032	44.8	1070	52.4	982	58.2
Not working	1161	50.4	862	42.2	611	36.2
Homemaker/caregiver	25	1.1	26	1.3	20	1.2
Volunteer	8	0.4	4	0.2	8	0.5
Retired	76	3.3	80	3.9	66	3.9
Total:	2302		2042		1687	

Table 4. School Status After Burn Injury, Participants 5–17 Years of Age

	6 Months		12 Months		24 Months	
School Status After Burn Injury, Participants, 5–17	Number of Cases	%	Number of Cases	%	Number of Cases	%
Same program	340	74.6	324	80.0	313	78.0
New program	44	9.7	43	10.6	65	16.2
Did not resume school	53	11.6	29	7.2	17	4.2
Returned in individual program/home school	19	4.2	9	2.2	6	1.5
Total:	456		405		401	

Physical and Mental Health After Burn Injury

Figure 3. Mean VR-12/SF-12 Physical and Mental Component Scores, Adults

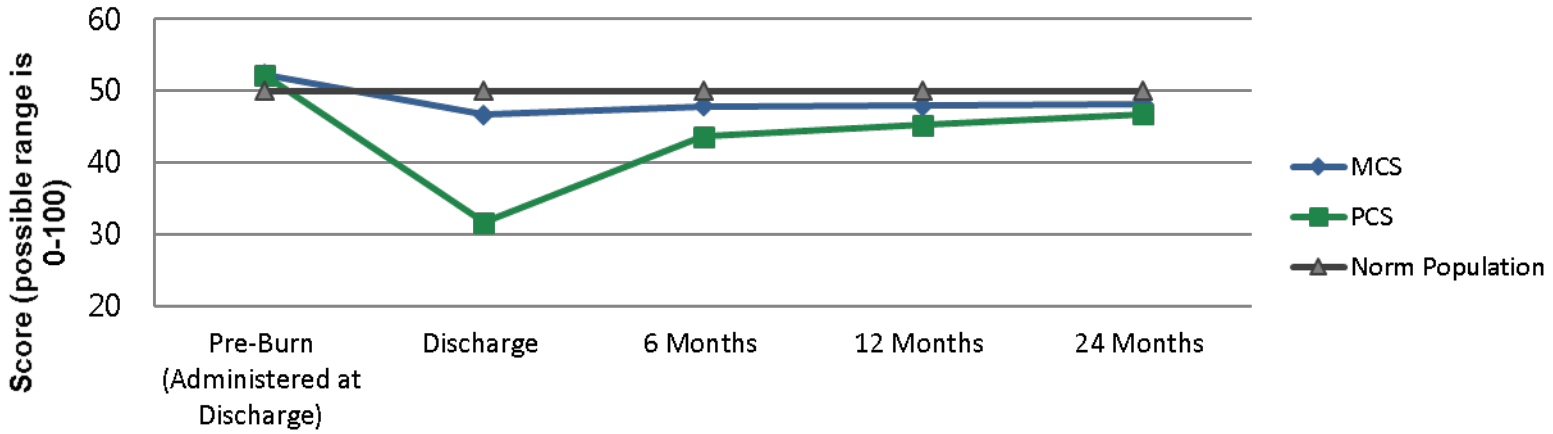


Table 5. Mean SF12 Physical and Mental Component Scores, Participants Ages 14 and Over

Mean SF12* Scores, Participants Ages 14 and Over	Pre-Burn (Administered at Discharge)		Discharge		6 Months		12 Months		24 Months	
	Mean	N	Mean	N	Mean	N	Mean	N	Mean	N
MCS	52.3	2,253	46.7	2,215	47.8	1,580	47.9	1,462	48.2	1,270
PCS	52.2	2,253	31.6	2,215	43.6	1,580	45.2	1,462	46.8	1,270

Representativeness of the BMS National Longitudinal Database

- Generalizability of BMS findings depend on the degree to which the BMS reflects the general population of people with burn injury in the US
- 2007 publication found the BMS National Longitudinal Database to be representative of the larger National Burn Repository database, with both internal and external validity shown in this comparison[1]
- A follow-up representativeness study is underway and will be completed in 2019

1. Lezotte, D. C., Hills, R. A., Heltshe, S. L., Holavanahalli, R. K., Fauerbach, J. A., Blakeney, P., . . . Engrav, L. H. (2007, December). Assets and liabilities of the Burn Model System data model: A comparison with the National Burn Registry. *Archives of Physical and Medical Rehabilitation, 88* (12 Suppl. 2), S7–S17.

BMS Site-Specific Studies: 2017-2022

- Boston-Harvard BMS Center (BHBIMS):
  - A study aiming to create longitudinal social recovery trajectories using the LIBRE Profile
  - Established trajectories will promote determination of burn survivor needs on an individual and population basis, as well as foster the design and assessment of resources and interventions in these domains.

BMS Site-Specific Studies: 2017-2022

- Northwest Regional Burn Model System Center (NWRBMS):
  - A project that establishes a web-based dissemination platform to provide education on the challenges and processes encountered after a significant burn injury.
  - The target audiences for this collaborative dissemination project include burn survivors, families, employers, medical professionals, case managers, third-party payers, and agencies involved with worker's compensation and vocational rehabilitation.
  - The NWRBMS is also conducting a prospective randomized trial examining virtual-environment home rehabilitation.

BMS Site-Specific Studies: 2017-2022

- North Texas BMS Center (NTBRMS):
  - A study that examines Vitamin D deficiency in adult burn survivors.
  - This study aims to compare low dose Vitamin D replacement to high dose to evaluate its effect on levels of Vitamin D in adult patients with major burn injury, and to determine if it improves common burn-related symptoms.

BMS Site-Specific Studies: 2017-2022

- UTMB & Shriner's BMS Center:
  - A study assessing the relationships and associations between psychosocial health and molecular predictors; habitual physical activity; and insulin sensitivity/resistance.
  - These physiological characterizations will be evaluated for associations or relationships with psychosocial health in response to the various anabolic therapies administered to burned patients, and will be explored from admit to 25 years post-burn.

Partnerships, Capacity Building, and Stakeholder Involvement

Partnerships

- The BMS program has established partnerships to increase the overall impact of research, information dissemination, and training of clinicians, researchers, and policy makers
- Past collaborations to improve capacity include:
  - The Pacific Institute for Research and Evaluation to determine QALY (quality adjusted life years) after thermal injuries
  - The Safety and Health Assessment and Research for Prevention (SHARP) program to identify high-risk industries for future research and prevention efforts

Current & Past Activities

- Working with both the American Burn Association (ABA) and the Phoenix Society to ensure that NIDILRR funded research addresses issues relevant to persons with burn injuries
- Collaboration between the BMS, ABA and the US Army Institute of Surgical Research to examine cognitive function after burn injury
- Partnership with ABA to arrange 2016 State of the Science Conference
  - Focused on late effects of acute patient and condition related conditions

Stakeholder Involvement

- Who are the Burn Model Systems stakeholders?
  - Burn survivors
    - Phoenix Society members
    - BMS Consumer Advisory Board membership (CAB)
  - Family members
    - BMS Consumer Advisory Board members (CAB)
  - Clinicians & Researchers
    - American Burn Association collaborators
      - 2006 and 2016 State of the Science conferences
  - Employers
  - Labor and Industries / Workers' Compensation Case managers

Stakeholder Involvement

- BMS research program development
  - Consumer Advisory Board (CAB) involvement
    - Utilized technology to advise direction and provide critique
  - 2006 and 2016 State of the Science
    - Focus group discussions to identify domains of research interest
    - Element of Participatory Action Research
- Review research progress and identify future directions
  - Phoenix Society
    - annual BMS Project Directors' meeting
    - 2006 & 2016 SOS symposium
  - Collaboration on site-specific BMS projects

Stakeholder Involvement

- Education
  - Burn-specific fact sheets concerning recovery issues
    - Participation includes content review, relevance and consumer-testing
    - Eleven current fact sheets reviewed every 5 years
    - Three new fact sheets *in development* in 2016
  - Burn prevention efforts
  - Utilizing social media to reach a larger audience
  - Representation on the BMS Knowledge Translation Committee
    - Collaborative projects with MSKTC and KTDRR
      - Hot Topic video ‘Employment after Burn Injury’
      - Webcast production ‘Returning to work after Burn Injury: From Research to Vocational Rehabilitation Practice’

Burn Survivors

- Survivors Offering Assistance in Recovery (Phoenix Peer Support Program)
- Burn Survivor Support Groups at BMS centers
- Involvement of survivor focus groups guiding BMS center activities, including research and dissemination
- Greater representation and participation at the Burn Research State of the Science Meeting

Capacity Building

- Longevity of the National Burn Injury Model System database
  - In existence since 1994
  - Nearly 6,000 individuals followed beyond the acute phase of recovery for issues within multiple domains:
    - Health / Function
    - Employment / Community re-integration
  - Research sharing plan:
    - SOP available to non-BMS researchers for interrogation
      - eg Miller, T., et al. (2013). "Quality-of-life loss of people admitted to burn centers, United States." Qual Life Res **22**(9): 2293-2305.

Capacity Building

- Training

Table 6. Fellows and Trainees Receiving Training from BMS Centers

	UW	Boston	JHU	UTSW	UTMB
Years of Funding	1994-2022	2012-2022	1997-2012	1994-2022	1997-2022
Burn Surgery Fellows	28	8	45	61	49
Psychology and Psychiatry	Fellows – 48 Residents – >86	2	Fellows – 15 Residents – 52	3 – Post doc	Fellows - 3
Physiatry	2	13	15	182	0
Research	8	17	0	0	9

- Dissemination
  - Trainees transfer BMS philosophy to practices nationally and internationally

Changing the field of burn research

- BMS research improved pain management and physical function:
  - Virtual reality is affordable safe and effective for treating burn related contractures by reducing pain and improving range of motion
  - Although the incidence of neuropathy has not changed, it is now clear that the prognosis of burn related mononeuropathy is generally good

Changing the field of burn research

- Heterotopic ossification remains a rare, difficult to treat burn complication. Recent research has shown that it is ten times more common in the military than in civilians and a new model for predicting HO. This will allow for expanded research efforts into treatment.
- Deep third degree hand burns can cause catastrophic impairment after burn injury. BMS studies have demonstrated that despite these devastating injuries, the majority of individual regain function

Changing the field of burn research

- Through BMS research propranolol has become a good standard for decreasing muscle mass loss in children
- Inpatient rehabilitation facilitates discharge to home among the elderly
- Exercise protocols for restoring lean body mass have been established

Changing the Structure of the ABA

- Burn Research State of the Science meetings
  - Creation of the Aftercare Reintegration Committee (ARC) - a Joint Committee of the American Burn Association and the Phoenix Society for Burn Survivors
- ARC Forum presentations each year at the ABA national meeting
  - Focus on burn survivors and families

Changing the Structure of the ABA

- Improved awareness of NIDILRR throughout the organization
- Involvement of BMS centers and personnel:
  - Past presidents of the ABA from the BMS centers
  - ABA committees
  - Workshops
  - Post graduate sessions
  - Symposium
  - Special Interest Groups
  - BMS research presentations
  - Moderators and plenary speakers

Dissemination and Knowledge Translation

Dissemination Activities

- The BMS program disseminates evidence-based information to patients, family members, health care providers, educators, policymakers and the general public by:
  - Peer-reviewed publications
  - Presentations at regional, national and international multi-disciplinary conferences
  - Newsletters with BMS research and center updates
  - Outreach satellite clinics for patients living in rural areas
  - Peer support groups
  - Social media (Facebook, Twitter)
  - BMS center websites
  - Peer- and consumer-tested fact sheets (14 available as of 2018)
  - Quick Reviews
  - Multi-media products
  - Annual publication of BMS Facts and Figures

Dissemination Activities (cont.)

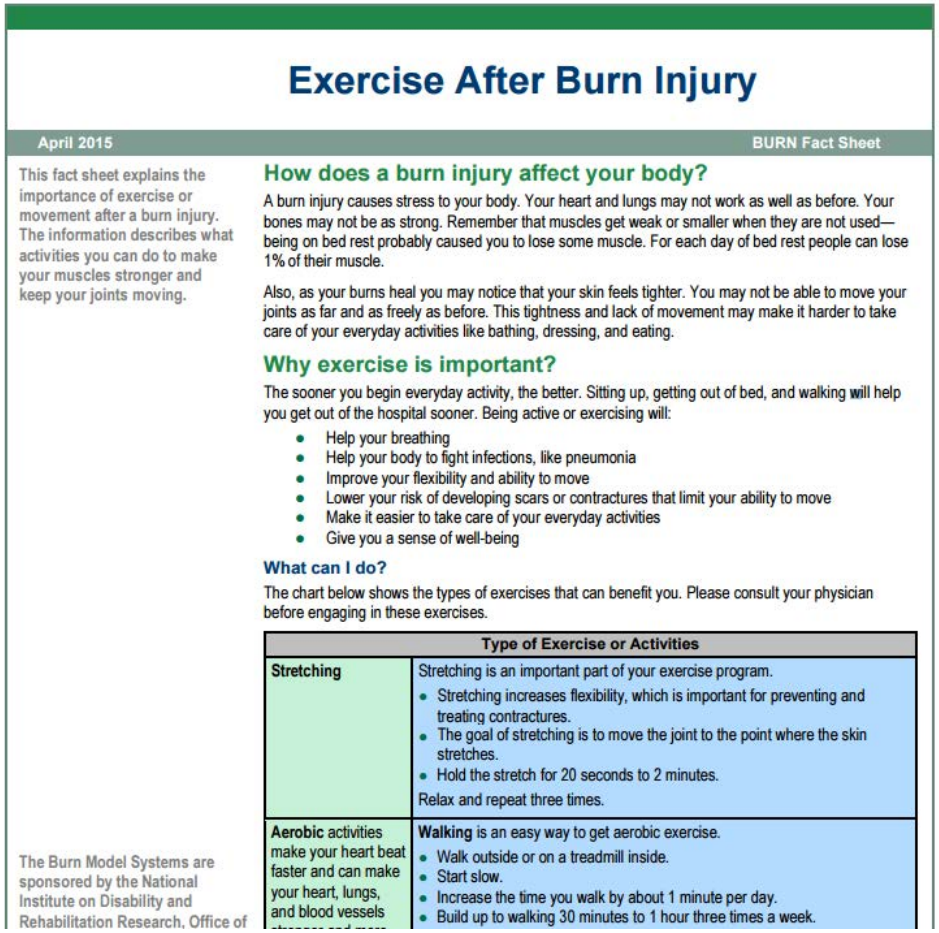
- The BMS program also collaborates with the NIDILRR-funded Model Systems Knowledge Translation Center to promote adoption of research findings by rehabilitation professionals, policymakers, persons with burn injuries and their family members. http://www.msktc.org/

Factsheet Overview:

(available in English & Spanish)

- Sleep Problems
- Psychological Distress
- Body Image
- Managing Pain
- Social Interactions
- Employment
- Building resilience in children with burns
- Wound Care and Scars
- Itchy Skin after Burn Injury
- Resilience
- Return to school
- Exercise
- Healthy Eating

Factsheet Example



Exercise After Burn Injury

April 2015 — BURN Fact Sheet

This fact sheet explains the importance of exercise or movement after a burn injury. The information describes what activities you can do to make your muscles stronger and keep your joints moving.

How does a burn injury affect your body?

A burn injury causes stress to your body. Your heart and lungs may not work as well as before. Your bones may not be as strong. Remember that muscles get weak or smaller when they are not used—being on bed rest probably caused you to lose some muscle. For each day of bed rest people can lose 1% of their muscle.

Also, as your burns heal you may notice that your skin feels tighter. You may not be able to move your joints as far and as freely as before. This tightness and lack of movement may make it harder to take care of your everyday activities like bathing, dressing, and eating.

Why exercise is important?

The sooner you begin everyday activity, the better. Sitting up, getting out of bed, and walking will help you get out of the hospital sooner. Being active or exercising will:

- Help your breathing
- Help your body to fight infections, like pneumonia
- Improve your flexibility and ability to move
- Lower your risk of developing scars or contractures that limit your ability to move
- Make it easier to take care of your everyday activities
- Give you a sense of well-being

What can I do?

The chart below shows the types of exercises that can benefit you. Please consult your physician before engaging in these exercises.

Type of Exercise or Activities	
Stretching	Stretching is an important part of your exercise program. • Stretching increases flexibility, which is important for preventing and treating contractures. • The goal of stretching is to move the joint to the point where the skin stretches. • Hold the stretch for 20 seconds to 2 minutes. Relax and repeat three times.
Aerobic activities make your heart beat faster and can make your heart, lungs, and blood vessels	**Walking** is an easy way to get aerobic exercise. • Walk outside or on a treadmill inside. • Start slow. • Increase the time you walk by about 1 minute per day. • Build up to walking 30 minutes to 1 hour three times a week.

The Burn Model Systems are sponsored by the National Institute on Disability and Rehabilitation Research, Office of

Fact Sheet Downloads

Table 7. Fact sheet unique views

Fact Sheet	2012 Unique Views	2013 Unique Views	2014 Unique Views	2015 Unique Views	2016 Unique Views	2017 Unique Views	2018 Unique Views	TOTAL Unique Views
Itchy Skin after Burn Injury		16,272	44,696	57,815	62,820	58,209	58,680	298,492
Wound Care and Scar Management after Burn Injury	278	9,417	38,910	39,467	43,941	17,392	4,561	153,966
Managing Pain after Burn Injury	120	5164	25925	38661	37782	30303	21038	158,993
Understanding and Improving Body Image After Burn Injury	254	2,272	8,385	13,991	20,074	17,621	12,067	74,664
Psychological Distress after Burn	146	874	2,913	5,687	7,724	5,659	3,687	26,690
Exercise and Burn Injury				1,198	6,853	10,196	11,402	29,649
Sleep Problems after Burn Injury	119	374	803	1,466	1,751	1,918	2,755	9,186
Healthy Eating after burn - Adults					15	3846	12935	16,796
Employment after Burn Injury	114	376	571	681	1,112	974	1,158	4,986
Social Interaction after Burn Injury	124	366	443	540	375	437	509	2,794
Healthy Eating After Burn - Children					18	1,008	2,629	3,655
Going Back to School After a Major Burn Injury				210	317	446	928	1,901
Help Your Child Recover—Build				157	269	335	442	1,203
PTSD After Burn Injury						514	717	1,231
Scar Management					8	250	560	818
Understanding Burn Injury							354	354
Wound Care							703	703

BMS Publications

- Over 200 studies have been published in peer-reviewed publications utilizing BMS data since the start of the program in 1993
- Publications include:
  - Pruritis of adult burn survivors: post-burn prevalence and risk factors associated with increased intensity
  - Assault and substance abuse characterize burn injuries in homeless patients
  - Prevalence of major psychiatric illness in young adults who were burned as children
  - Burns as a result of assault: associated risk factors, injury characteristics, and outcomes
  - Medical and psychological aspects of rehabilitation from burn injury

Publications from Site-Specific Projects

Table 8. Twelve site-specific manuscripts with over 100 citations, and their topic area(s)

Manuscript Title	Number of Citations through 10/2018	Topic Area
Clinical evaluation of an acellular allograft dermal matrix in full-thickness burns	522	Rehab/functional outcomes/scar, translational medicine
The pathophysiologic response to severe burn injury	455	Burn pathophysiology
Use of virtual reality for adjunctive treatment of adult burn pain during physical therapy: A controlled study	292	Pain
Burn rehabilitation: state of the science	274	Rehab/functional outcomes/scar
Effectiveness of virtual reality-based pain control with multiple treatments	255	Pain
What is the prevalence of hypertrophic scarring following burns	241	Rehab/functional outcomes/scar therapy
Personality predictors of injury-related PTSD	228	Psychology
Burn size determines the inflammatory and hypermetabolic response	223	Burn pathophysiology, hypermetabolism
Respiratory management of inhalation injury	208	Burn pathophysiology
Effect of a 12-wk resistance exercise program on skeletal muscle strength in children with burn injuries	193	Rehab/functional outcomes/scar
The 2003 clinical research award: Visible vs. hidden scars and their relation to body esteem	168	Psychology
The effect of early body image dissatisfaction on subsequent psychological and physical adjustment following disfiguring injury	152	Psychology

Table adapted from "NIDRR Burn Injury Model Systems: History and Contributions to Clinical Service and Research," developed by BHBIMS

Accomplishments

BMS Research Findings:

- Virtual reality is affordable safe and effective for treating contractures by reducing pain and improving range of motion
- The prognosis for recovery of mononeuropathies is good
- The majority of those with deep full thickness hand burns have good hand function at more than 3 years post burn
- Propranolol decreases muscle loss in children
- Older age is a key risk factor for non independence at dc
- Adults with an amputation are 8x less likely to be employed at one year post injury
- Aerobic exercise reduces loss of muscle mass in children
- A scoring system has been developed to predict development of HO
- Custom pressure garments may be an effective treatment for hypertrophic scarring
- Duroc porcine partial thickness wound repair has been validated as a model for hypertrophic scar
- Pain and insomnia have a significant impact on quality of life and return to work

Accomplishments: Research

- Efficacy of custom-fit pressure garments after burns:
  - Established that pressure garment therapy is effective
- Impact of immersive virtual reality:
  - Established the value of the method, which is now used across North America, Australia, and the United Kingdom
- Development of an animal model for scar research:
  - Established the Duroc/Yorkshire porcine model of scarring, which may lead to effective treatment/prevention
- Research published in peer-reviewed journals (will be further highlighted in upcoming dissemination section)

Additional Accomplishments: Research

- Over 6,000 individuals enrolled in National Longitudinal database
- Increased rate of retention at 6, 12, and 24 months by at least 10% over the past 10 years
- High quality data collected
  - Comprehensive data collection includes multiple important domains
  - Psychometrically sound measures, including IRT based
  - Rigorous data management

Accomplishments: Capacity Building

- BMS participation in the ABA after care committee
- BMS plays a key role in the ongoing shift of burn research from acute care focus to recovery, rehabilitation, and community reintegration focus
- State of the Science Conference and subsequent white paper in 2006
- Improving burn community knowledge of BMS database (available to public)

Accomplishments: Knowledge Translation

- BMS Booth at ABA annual conference (annually since 2013)
- Facts and figures and the annual report published on the website and distributed to ABA and Phoenix Society
- Factsheets disseminated to patients in clinics in addition to online dissemination
- Development of “Hot Topic” module regarding returning to work after a burn injury, including video and resources
- Numerous presentations at the American Burn Association annual conference and other meetings every year

Future

Directions

Future Directions: Research

- Further examination of representativeness of database by comparing BMS National Longitudinal database to the national TRACs database
- The BMS has recently expanded long term follow-up of BMS National Longitudinal Database to include every 5 years post injury and continues to focus on follow-up of long term survivors of burn injury
- Continued enrollment and follow-up of participants in National Longitudinal database and site-specific studies

Future Directions: Capacity Building

- Formalizing procedure to operationalize relationship between BMS and Phoenix Society
- Combining data with Uniform Data System for Medical Rehabilitation to learn more about relationship between functioning at discharge and long-term health outcomes
- Collaborating on a joint database project with Shriner's
- Increasing visibility of BMS National Longitudinal database and its availability to the public

Future Directions: Knowledge Translation

- Extending dissemination activities to burn centers nationally
- Organizing BMS session/panel at the World Burn Congress
- Publishing letters to the editor, which are brief snapshots of the data collected by the BMS in the Journal of Burns
- Involving people with injury in BMS work: collaboration with Phoenix Society, including Phoenix Society's close work on existing projects such as LIBRE
- Developing new fact sheets, systematic reviews, peer reviewed publications
- Continue peer support groups, maintenance of BMS websites, newsletters, and social media platforms

Vision for Expansion of the BMS

NIDILRR funds Three Model Systems

- Spinal Cord Injury (SCI) established 1970
  - 14 funded centers with a data and statistical center
  - US estimated incidence of injury: 12,000/year
- Traumatic Brain Injury (TBI) established 1987
  - 16 funded centers with a data and statistical center(plus 4 follow up centers)
  - US estimated incidence of injury: 1.7 million injured; 275,000 hospitalizations; 52,000 deaths
- Burn Model system (BMS) established 1993
  - 4 funded centers with a data and statistical center
  - US estimated incidence of injury: 1.1 million injured; 50,000 hospitalizations; 4,500 deaths

Vision for Expansion of the BMS

- NIDILRR Model System Funding
  - Increased funding is needed for additional BMS centers. Funding for BMS centers (4) has not kept pace with the other two model systems (SCI-14, TBI-16)
  - Increasing BMS center funding sends a message of equal value and importance in relation to the other two Model Systems (SCI & TBI)
  - Increased funding provides the opportunity for increased research and improved treatment and recovery
  - Increased funding can provide additional opportunities for creativity and can improve productivity and outcomes

Vision for Expansion of the BMS

- NIDILRR Model System Funding
  - Adding additional BMS centers would increase the validity that data collected is truly representative of the population. Additional centers should provide:
    - Geographic diversity across the U.S.
    - Cultural and racial diversity
    - Social-Economic diversity
    - Age diversity
      - ABA National Burn Registry states >30% of burn injuries occur in patients <20 years of age, therefore hospitals specializing in pediatrics should be valued centers

Vision for Expansion of the BMS

- Clinical trials are imperative to continue to advance burn care and treatment. Multi-center trials are needed to change current standards of practice.
- Clinical trials are needed for acute burn care research
  - Anabolic agents to modulate the hypermetabolic response to burn injury
    - Pharmacologic drug administration
    - Diet and nutritional supplementation
    - Early exercise, movement and rehabilitation
- Clinical trials are needed for Rehabilitation, Recovery and Reintegration
  - Standardized rehabilitation and intensive exercise and endurance training. Currently standard of practice treatment is only performing range of motion and activities of daily living
  - Treatment and management of burn scars that can cause physical and psychological disabilities
  - Clinical practice regimens and therapies to improve recovery and reintegration back into society

Vision for Expansion of the BMS

- Options for increased grant funding
  - Increase total number of BMS centers
  - Fund follow-up centers (previous and currently funded centers) to continue to collect data
  - Tiered funding to allow centers to apply for grants based on institutional desire and ability to participate (multiple grant options within a grant). A maximum funding level would be set for each tier.
  - Collaborative funding efforts with other burn organizations (ABA, Phoenix Society)

Questions/comments?

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