



The Value of Patient Registries to Advance Basic and Translational Research in the Area of Traumatic Brain Injury

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The number of individuals affected by traumatic brain injury (TBI) is growing globally. TBIs may cause a range of physical, cognitive, and psychiatric deficits that can negatively impact employment, academic attainment, community independence, and interpersonal relationships. Although there has been a significant decrease in the number of injury related deaths over the past several decades, there has been no corresponding reduction in injury related disability over the same time period. We propose that patient registries with large, representative samples and rich multidimensional and longitudinal data have tremendous value in advancing basic and translational research and in capturing, characterizing, and predicting individual differences in deficit profile and outcomes. Patient registries, together with recent theoretical and methodological advances in analytic approaches and neuroscience, provide powerful tools for brain injury research and for leveraging the heterogeneity that has traditionally been cited as a barrier inhibiting progress in treatment research and clinical practice. We report on our experiences, and challenges, in developing and maintaining our own patient registry. We conclude by pointing to some future opportunities for discovery that are afforded by a registry model.

Keywords: traumatic brain injury, outcome, registry, intervention, heterogeneity

INTRODUCTION

Traumatic brain injuries (TBI) are on the rise globally with 69 million individuals worldwide estimated to sustain a brain injury each year (Dewan et al., 2018). TBIs can cause a constellation of interacting physical, cognitive, and psychiatric deficits that can negatively impact employment, academic achievement, community independence, and interpersonal relationships, leading to longterm disability and poor functional outcomes. While there has been a significant decrease in the number of injury-related deaths over the past several decades, there has been no corresponding reduction in injury-related disability despite considerable efforts in research and clinical spheres (Roosenbeek et al., 2013).

There are a number of factors contributing to the variable and suboptimal outcomes among individuals with TBI. One frequently cited and long recognized obstacle to significant

Erin Sullivan-Baca, Rachael L. Ellison

Translational Research in Traumatic Brain Injury Daniel Laskowitz,2015 Translational Research in Traumatic Brain Injury Daniel Laskowitz, Gerald Grant,2016-04-21 Traumatic brain injury TBI remains a significant source of death and permanent disability contributing to nearly one third of all injury related deaths in the United States and exacting a profound personal and economic toll Despite the increased resources that have recently been brought to bear to improve our understanding of TBI the developme Pediatric Traumatic Brain Injury Vicki Anderson, Keith Owen Yeates, 2010-02-04 Traumatic brain injury TBI is a leading cause of death and disability in children and adolescents around the world and represents a global public health issue Major improvements in the medical treatment of the initial injury have increased survival rates resulting in the focus shifting to consider the subsequent and longer term cognitive emotional and behavioral consequences for the recovering child or adolescent These disabilities if left untreated continue into adulthood with consequent economic and societal costs This book reviews the research into the consequences of TBI emphasizing the translation of new understanding into effective treatments and interventions and identifying promising areas for further study This will be essential reading for neuropsychologists neurologists psychiatrists clinical psychologists and pediatricians

Advancement and New Understanding in Brain Injury Zamzuri Idris, 2021-07-07 This book covers the latest developments in the understanding and treatment of traumatic brain injury Various world experts authored the chapters that comprise a wealth of updated information on intracranial pressure monitoring and diagnostic methods neuroinflammatory responses in traumatic brain injury cerebral palsy and Covid 19 related brain disorder pathogenesis and prevention of fetal neonatal infant and child brain injury hyperbaric oxygenation treatment the engineering and modeling of head injury systematic review on early tracheostomy intracranial aneurysm in tuberous sclerosis complex and the neurobehavioral and cognitive aspects of brain injury With these complex topics every clinician scientist and researcher will find this book invaluable in understanding the latest improvements and advances in the diagnosis and treatment of traumatic brain injury Manual of Traumatic Brain Injury, Third Edition Felise S. Zollman, 2021-07-22 The third edition of Manual of Traumatic Brain Injury offers a thorough revision of the popular evidence based guide to understanding and managing all levels of traumatic brain injury Comprehensive in scope and concise in format this reference describes the spectrum of injury from mild to severe and the continuum of care from initial injury to management of chronic sequelae Chapters are designed with a practical clinical focus for targeted retrieval of content by topic area and for self review The text is organized into five sections Part I addresses fundamental concepts necessary for understanding the underpinning of clinical decision making Part II is dedicated to mild TBI including sport related concussion with chapters covering topics from natural history to associated somatic disorders post concussion syndrome and PTSD Part III covers moderate to severe TBI and details prehospital emergency and ICU care rehabilitation treatment of related conditions and postinjury outcomes Part IV focuses on TBI

related complications including posttraumatic seizures spasticity behavioral and sleep disturbances and chronic traumatic encephalopathy CTE Part V reviews special considerations in selected populations such as pediatric TBI and TBI in the military as well as medicolegal and ethical considerations in TBI complementary and alternative medicine and return to work considerations Each chapter includes boxed Key Points which underscore major clinical takeaways Study Questions to facilitate self assessment and further emphasize core chapter content and an Additional Reading list for a deeper dive into chapter concepts Significant updates incorporating recent advancements in the field combined with the clinical acumen of its experienced contributors make this third edition the essential manual for healthcare professionals caring for individuals with traumatic brain injury Key Features Succinct format encourages targeted access to key clinical information Completely revised and updated third edition reflects current state of the art advancements Added content areas such as a new chapter dedicated to substance abuse and TBI expand the scope of material addressed Newly added multiple choice Study Questions in each chapter facilitate self assessment of mastery of chapter material The Neuroscience of Traumatic Brain Injury Rajkumar Rajendram, Victor R Preedy, Colin R. Martin, 2022-05-27 Diagnosis and Treatment of Traumatic Brain Injury will improve readers understanding of the complexities of diagnosis and management of traumatic brain injuries Featuring chapters on drug delivery different treatments and rehabilitation this volume discusses in detail the impact early diagnosis and effective management has on the long term prognosis of these injuries and the lives of those affected This book will be relevant for neuroscientists neurologists clinicians and anyone working to better understand these injuries Traumatic brain injury has complex etiology and may arise as a consequence of physical abuse violence war vehicle collisions working in the construction industry and sports Cellular Molecular Physiological and Behavioral Aspects of Traumatic Brain Injury will improve readers understanding of the detailed processes arising from traumatic brain injury Featuring chapters on neuroinflammation metabolism and psychology this volume discusses the impact of these injuries on neurological and body systems to better understand underlying pathways This book will be relevant for neuroscientists neurologists clinicians and anyone working to better understand traumatic brain injury Diagnosis and Treatment of Traumatic Brain Injury Covers both the diagnosis and treatment of traumatic brain cord injury Contains chapter abstracts key facts dictionary and summary points to aid in understanding Features chapters on epidemiology and pain Includes MRI usage biomarkers and stem cell and gene therapy for management of spinal cord injury Discusses pain reduction drug delivery and rehabilitation Cellular Molecular Physiological and Behavioral Aspects of Traumatic Brain Injury Summarizes the neuroscience of traumatic brain injury including cellular and molecular biology Contains chapter abstracts key facts dictionary and summary points to aid in understanding Features chapters on signaling and hormonal events Includes plasticity and gene expression Examines health and stress behaviors after traumatic brain injury The LDN Book, Volume Two Linda Elsegood, 2020 A drug that is simultaneously affordable devoid of severe side effects and applicable to a wide range of diseases is one not often found in

the modern pharmaceutical landscape But as medical professionals and researchers alike have found Low Dose Naltrexone LDN boasts this remarkable combination LDN originally prescribed in higher doses as a treatment for opioid addiction works by blocking opioid receptors thereby stimulating the production of endorphins mitigating the inflammatory process and stabilizing the immune response Prescribed off label and administered in small daily doses this generic drug has proven useful in treating many different ailments Expanding on the information presented in The LDN Book Volume 1 which showcased LDN s efficacy in treating conditions such as lupus thyroiditis autism spectrum disorder and chronic fatigue Volume 2 highlights the latest clinical trials case studies and research on LDN More than a dozen medical professionals explain how they are using LDN to help patients suffering from chronic pain Parkinson's disease dermatologic conditions traumatic brain injury Lyme disease and more The LDN Book Volume 2 is both a resource for practitioners pharmacists and patients and a renewed call for further research on a little known drug with big potential **Neuropsychology of Women** Erin Sullivan-Baca, Rachael L. Ellison, 2025-05-15 Women have long been underrepresented in scientific research which has limited our understanding of how they may be uniquely impacted by various medical psychological and neurocognitive conditions Due to this limitation neuropsychological training and practice has historically fallen short of acknowledging potential sex and gender differences and effectively incorporating this knowledge into evaluations and treatment recommendations Fortunately in recent years contemporary research has begun to draw more focus on unique biopsychosocial factors impacting the epidemiology presentation neurocognitive profile and treatment implications for women with neuropsychological concerns In an age of increased focus on diversity equity and inclusion DEI in the field of neuropsychology compounded by the background of everchanging socio political factors in the U S either supporting or opposing this focus it is crucial that clinical neuropsychologists gain the knowledge and skills to provide individualized gender informed care to women patients It is imperative for neuropsychology as a specialty to champion this initiative as leading experts in the intersection of cognition mental health and disorders pertaining to the brain which has the potential to inform clinical practice and research in related fields such as medicine and neuroscience Neuropsychology of Women Considerations for Clinical Care Research provides an overview of the current research informed knowledge base on how different conditions encountered in neuropsychological practice uniquely present in women patients Chapters are authored by some of the foremost neuropsychological researchers and clinicians of today spanning topics inclusive of both those impacting both genders with a focus on the understudied and unique clinical implications related to women as well as those disproportionately affecting women These range from specific neurodegenerative conditions such as Alzheimer's disease and movement disorders to acute events like stroke and traumatic brain injury to chronic conditions including autoimmune disorders and epilepsy all consolidating the literature into a concise and accessible format Chapters focusing on chronic health conditions and issues relating to pregnancy and menopause supplement those focused on neurological conditions to

help clinical providers conceptualize patients through a comprehensive neuropsychological lens and to help researchers understand where opportunities lie for further exploration For those new to the field of neuropsychology including students and trainees Neuropsychology of Women Considerations for Clinical Care Research extends beyond traditional texts to incorporate issues of DEI through an intentional and organic approach This is the first book of its kind in over a decade and the most comprehensive resource available to clinical neuropsychologists seeking to provide the highest standard of inclusive Brain Injury Medicine, Third Edition Nathan D. Zasler, Douglas I. Katz, Ross D. practice to women patients Zafonte, 2021-09-01 This updated textbook was much needed as there has been increased attention in recent years toward brain injuries The book provides updated guidelines and clinical practice recommendations that support the intended audience of trainees and current practitioners. This update makes it the current standard text for any brain injury specialist Doody's Review Service 4 stars This revised and greatly expanded Third Edition of Brain Injury Medicine continues its reputation as the key core textbook in the field bringing together evidence based medicine and years of collective author clinical experience in a clear and comprehensive guide for brain injury professionals Universally praised as the gold standard text and go to clinical reference the book covers the entire continuum of care from early diagnosis and assessment through acute management rehabilitation associated medical and quality of life issues and functional outcomes With 12 new chapters and expanded coverage in key areas of pathobiology and neuro recovery special populations sport concussion disorders of consciousness neuropharmacology and more this state of the science resource promotes a multi disciplinary approach to a complex condition with consideration of emerging topics and the latest clinical advances Written by over 200 experts from all involved disciplines the text runs the full gamut of practice of brain injury medicine including principles of public health and research biomechanics and neural recovery neuroimaging and neurodiagnostic testing sport and military prognosis and outcome acute care treatment of special populations neurologic and other medical complications post injury motor and musculoskeletal problems post trauma pain disorders cognitive and behavioral problems functional mobility neuropharmacology and alternative treatments community reentry and medicolegal and ethical issues Unique in its scope of topics relevant to professionals working with patients with brain injury this third edition offers the most complete and contemporary review of clinical practice standards in the field Key Features Thoroughly revised and updated Third Edition of the seminal reference on brain injury medicine Evidence based consideration of emerging topics with new chapters covering pathobiology biomarkers neurorehabilitation nursing neurodegenerative dementias anoxic hypoxic ischemic brain injury infectious causes of acquired brain injury neuropsychiatric assessment PTSD and capacity assessment Multi disciplinary authorship with leading experts from a wide range of specialties including but not limited to physiatry neurology psychiatry neurosurgery neuropsychology physical therapy occupational therapy speech language pathology and nursing New online chapters on survivorship family perspectives and resources for persons with brain injury and their caregivers Purchase

includes digital access for use on most mobile devices or computers Targeted Therapy for the Central Nervous System Viral Patel, Mithun Singh Rajput, Jigna Samir Shah, Tejal Mehta, 2024-10-07 Targeted Therapy for the Central Nervous System Formulation Clinical Challenges and Regulatory Strategies presents research on various delivery methods of drugs to the central nervous system and brain This volume examines targeted therapies for neurodegenerative disorders and succinctly outlines the future of drug delivery systems highlighting significant advancements specifically relating to central nervous system delivery This book will be of great interest to researchers working in the field of neuroscience and pharmacology as well as clinicians pharmacists radiologists psychiatrists Provides a current thorough means on how drugs are delivered to the neurological system Figures a connection amongst the physiology of drug delivery pertaining to the central nervous system fundamentals of drug delivery and distribution principles Gives an accounting of clinical trials and regulatory approaches for the formulations targeting brain Cellular, Molecular, Physiological, and Behavioral Aspects of Traumatic Brain Injury Rajkumar Rajendram, Victor R Preedy, Colin R. Martin, 2022-05-10 Traumatic brain injury has complex etiology and may arise as a consequence of physical abuse violence war vehicle collisions working in the construction industry and sports Cellular Molecular Physiological and Behavioral Aspects of Traumatic Brain Injury will improve readers understanding of the detailed processes arising from traumatic brain injury Featuring chapters on neuroinflammation metabolism and psychology this volume discusses the impact of these injuries on neurological and body systems to better understand underlying pathways This book will be relevant for neuroscientists neurologists clinicians and anyone working to better understand traumatic brain injury Summarizes the neuroscience of traumatic brain injury including cellular and molecular biology Contains chapter abstracts key facts dictionary and summary points to aid in understanding Features chapters on signaling and hormonal events Includes plasticity and gene expression Examines health and stress behaviors after traumatic brain injury **Brain Neurotrauma** Firas H. Kobeissy, 2015-02-25 With the contribution from more than one hundred CNS neurotrauma experts this book provides a comprehensive and up to date account on the latest developments in the area of neurotrauma including biomarker studies experimental models diagnostic methods and neurotherapeutic intervention strategies in brain injury research It discusses neurotrauma mechanisms biomarker discovery and neurocognitive and neurobehavioral deficits Also included are medical interventions and recent neurotherapeutics used in the area of brain injury that have been translated to the area of rehabilitation research In addition a section is devoted to models of milder CNS injury including sports injuries Handbook of Neurorehabilitation and Principles of Science ,2009 Neurology Carlo Caltagirone, Fabrizio Piras, Paola Imbriani, 2021-06-24 Le patologie neurologiche sono sempre pi diffuse richiedono protocolli riabilitativi sempre pi raffinati e che siano basati su evidenze scientifiche I deficit prodotti da queste patologie possono produrre una compromissione del sistema nervoso alterandone le funzioni e determinando differenti gradi di disabilit La neuroriabilitazione prevede dunque l'impiego di sofisticate tecniche diagnostiche e l'applicazione di protocolli

di riabilitazione funzionale dei deficit volti a ottenere un ridimensionamento di specifiche disabilit Handbook of Neurorehabilitation and Principles of Neurology un volume suddiviso in quattro parti la prima e la seconda di carattere pi propedeutico sono rispettivamente dedicate alle basi neurobiologiche della neuroriabilitazione e ai principi generali della neuroriabilitazione motoria e cognitiva La terza parte invece dedicata alle complesse questioni che riguardano l organizzazione dei servizi erogati ai pazienti L ultima parte decisamente la pi ampia contempla tutte le patologie neurologiche che meritano un trattamento riabilitativo Ogni singola categoria nosologica viene presentata considerando dapprima i criteri diagnostici e poi illustrando i protocolli riabilitativi maggiormente indicati per ottenere la riduzione dei deficit e delle disabilit Il volume scritto da specialisti e dedicato a tutti gli operatori che lavorano in istituzioni biomediche che erogano servizi dedicati alla riabilitazione neurologica ha il pregio di delineare lo stato dell'arte e di offrire protocolli supportati dalle evidenze scientifiche prodotte dalle pi recenti ricerche in ambito clinico e neuroscientifico Neurological conditions are increasingly widespread requiring progressively more refined rehabilitation protocols based on scientific evidence The deficits produced by these conditions can impair the nervous system altering its functions and causing varying degrees of disability Neurorehabilitation therefore involves the use of sophisticated diagnostic techniques and the application of protocols for functional rehabilitation of deficits aimed at reducing specific disabilities Handbook of Neurorehabilitation and Principles of Neurology is split into four parts parts one and two are more propaedeutic in nature and focus respectively on the neurobiological basis of neurorehabilitation and the general principles of motor and cognitive neurorehabilitation Part three is devoted to the complex issues concerning the organization of services for patients The final and by far the largest part covers all the neurological disorders requiring rehabilitative treatment Each individual nosological category is presented by first considering the diagnostic criteria and then illustrating the most suitable rehabilitation protocols to obtain a reduction in deficits and disabilities Written by specialists and aimed at all healthcare professionals working in biomedical institutions that provide neurological rehabilitation services the book has the merit of outlining the state of the art and proposing evidence based protocols supported by the latest research in the clinical and neuroscientific field

Neurotrauma: New Insights into Pathology and Treatment John T. Weber, Andrew I.R. Maas, 2007-07-27 Neurotrauma is the leading cause of death and disability in young adults and the incidence in older patients is increasing Neurotrauma is also a field in medicine with one of the highest unmet needs Concentrated focused and multidisciplinary efforts are required to combat this important disease Exciting findings from basic research open opportunities for improving treatment results This volume presents a unique and comprehensive overview of the latest findings and insights on translational research in neurotrauma This book should be a must for any TBI or SCI researcher interested in translating their work to the clinic as well as to clinicians interested in the latest research findings which could provide novel treatment strategies for their patients Integrates results from research on traumatic brain injury and spinal cord injury bridging basic science and clinical

research Includes contributions from a worldwide panel of leading researchers and clinicians in the fields of TBI and SCI <u>Understanding Traumatic Brain Injury</u> Harvey Levin, David Shum, Raymond Chan, 2014-01-28 This timely book reports recent progress in research on traumatic brain injury TBI by leading investigators encompassing translational and clinical studies The text covers epidemiology pathophysiology brain imaging cognition behavioral sequelae and clinical trials of innovative treatments including new approaches to rehabilitation The range of TBI mechanisms represented in this cutting edge book includes closed head trauma and blast related injury and the spectrum of TBI severity Chapters offer a developmental perspective including the effects of TBI on cognitive development in children and outcome studies in adults Contributors from various countries provide a global perspective on this worldwide health problem The editors have synthesized the contents in a concluding chapter Researchers and clinicians will find this volume to be an informative authoritative reference for current TBI research New Insights and Perspectives on Traumatic Brain Injury: Integration, Translation and Multidisciplinary Approaches Zhou Zhou, Jifeng Cai, Xianping Du, Jian Shi, 2024-07-01 Traumatic brain injury TBI remains one of healthcare s most significant challenges and policy making TBI could not only lead to long term functional impairment but also a decrease in quality of life Lowering the mortality risk and benefitting survivors living quality remains the target of neurotrauma studies globally With the advent of novel TBI related clinical and basic research approaches diagnostics therapeutics research and novel and multidisciplinary methods have emerged Despite promising progress no completely effective treatment prevents or minimizes TBI and its related neurological and psychiatric sequelae Understanding the mechanisms underlying the pathophysiology treatment progress and clinically based translational and engineering research on TBI may pave the way for potential treatment targets diagnostic markers and preventive methods that ultimately lead to efficacious therapeutic strategies This Research Topic aims to disseminate high quality TBI and related research especially for the compositive and in depth study in integration translation and multidisciplinary approaches in TBI research including new technology and research methods in clinical neurology new findings in neuroendocrinology neuropathology and new development in neuropharmacology neurophysiology This Research Topic is focused on novel developments current challenges future perspectives and especially interdisciplinary research in the field of TBI

Neurotrauma Kevin Wang,2018-11-16 Neurotrauma A Comprehensive Textbook on Traumatic Brain Injury and Spinal Cord Injury aims to bring together the latest clinical practice and research in the field of two forms of trauma to the central nervous system namely traumatic brain injury TBI and spinal cord injury SCI This volume details the latest research and clinical practice in the treatment of neurotrauma in a comprehensive but easy to follow format Neurotrauma is a valuable resource for any clinician involved in caring for the TBI clinical research professionals researchers medical and graduate students and nurse specialists

New Therapeutics for Traumatic Brain Injury Kim Heidenreich,2016-09-27 New Therapeutics for Traumatic Brain Injury Prevention of Secondary Brain Damage and Enhancement of Repair and

Regeneration explores traumatic brain injury TBI a major cause of death and disability throughout the world The delayed nature of the secondary injury phase suggests that there is a therapeutic window for pharmacological interventions or other approaches to prevent progressive tissue damage and improve functional outcomes It is now apparent that therapeutic interventions should entail both protective and repair regeneration strategies depending on the phase of brain injury This book describes emerging experimental strategies for the treatment of TBI including new anti inflammatory or anti apoptotic therapeutics that limit brain damage and novel or repurposed drugs that enhance repair or regeneration of the brain after injury Comprehensive overview of basic approaches and translational development of new therapies for TBI Edited by a prominent TBI researcher that includes contributions by leading global researchers in the field Presents a great resource for researchers and practitioners to learn more about the many evolving preclinical studies and clinical trials currently underway and the challenges of bringing translational studies in TBI to the clinic Mechanisms of Neuroinflammation and Inflammatory Neurodegeneration in Acute Brain Injury Arthur Liesz, Christoph Kleinschnitz, 2015-11-13 Mechanisms of brain immune interactions became a cutting edge topic in systemic neurosciences over the past years Acute lesions of the brain parenchyma particularly induce a profound and highly complex neuroinflammatory reaction with similar mechanistic properties between differing disease paradigms like ischemic stroke intracerebral hemorrhage ICH and traumatic brain injury TBI Resident microglial cells sense tissue damage and initiate inflammation activation of the endothelial brain immune interface promotes recruitment of systemic immune cells to the brain and systemic humoral immune mediators e g complements and cytokines enter the brain through the damaged blood brain barrier These cellular and humoral constituents of the neuroinflammatory reaction to brain injury contribute substantially to secondary brain damage and neurodegeneration Diverse inflammatory cascades such as pro inflammatory cytokine secretion of invading leukocytes and direct cell cell contact cytotoxicity between lymphocytes and neurons have been demonstrated to mediate the inflammatory collateral damage in models of acute brain injury Besides mediating neuronal cell loss and degeneration secondary inflammatory mechanisms also contribute to functional modulation of neurons and the impact of post lesional neuroinflammation can even be detected on the behavioral level The contribution of several specific immune cell subpopulations to the complex orchestration of secondary neuroinflammation has been revealed just recently However the differential vulnerability of specific neuronal cell types and the molecular mechanisms of inflammatory neurodegeneration are still elusive Furthermore we are only on the verge of characterizing the control of long term recovery and neuronal plasticity after brain damage by inflammatory pathways Yet a more detailed but also comprehensive understanding of the multifaceted interaction of these two supersystems is of direct translational relevance Immunotherapeutic strategies currently shift to the center of translational research in acute CNS lesion since all clinical trials investigating direct neuroprotective therapies failed To advance our knowledge on brain immune communications after brain damage an interdisciplinary approach covered by

cellular neuroscience as well as neuroimmunology brain imaging and behaviora intricate mechanisms	al sciences is crucial to thoroughly depict the

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