



# moonrise

ONE FAMILY, GENETIC IDENTITY,  
AND MUSCULAR DYSTROPHY

PENNY WOLFSON

WINNER OF A NATIONAL MAGAZINE AWARD FOR FEATURE WRITING

# Moonrise One Family Genetic Identity And Muscular Dystrophy

**Karin Nielsen-Saines**



## **Moonrise One Family Genetic Identity And Muscular Dystrophy:**

Moonrise Penny Wolfson, 2003-03-26 Wolfson pens a deeply felt personal narrative of a mother whose son has muscular dystrophy set against the scientific and historical background of this tragic genetic illness Illustrations *Moonrise* Penny Wolfson, 2014-04-22 *Moonrise* is Penny Wolfson's first person account of her family her son Ansel and his progressive disability caused by the genetic disease Duchenne muscular dystrophy The journey begins when he is born and deemed a particularly beautiful and magical baby continues with the alarming possibility at the age of two of wrongness takes us through the diagnosis of disease and prognosis of early death and brings us to his adolescence where his parents are never sure if the moon is rising or setting over his life As she traces her son's development and the impact of his disability on her worldview she embarks on a quest to understand scientific advances and their implications The gene was isolated at approximately the time Ansel was diagnosed She also explores special education giftedness prenatal testing and the genetic links she shares with her mother sisters and son Questions about the disease causing mutation persist What does knowledge of the self on a molecular level mean Is genetic self knowledge our goal now much as knowledge of the psyche was in the last century *Moonrise* is an essential contribution to the dialogue about genetics as well as a deeply human story about a remarkable child and his family Muscular Dystrophy Clay Farris Naff, 2011-12-01 There are 8 different known types of this disorder and some Muscular Dystrophy can actually be discovered during pregnancy according to HRF This guidebook provides essential information on MD but also serves as a historical survey by providing information on the controversies surrounding its causes and first person narratives by people coping with MD Patients family members or caregivers explain the condition from their own experience The symptoms causes and treatments are explained in detail Essential to anyone trying to learn about diseases and conditions the alternative treatments are explored Each essay is carefully edited and presented with an introduction so that they are accessible for student researchers and readers *Brief Reference of Student Disabilities* Lee Brattland Nielsen, 2008-08-27 This updated edition provides information about common exceptionalities ADHD and bipolar disorder legal considerations and discussions on postsecondary transition NCLB and the reauthorization of IDEA 2004 **The Jeffrey Journey - 2010 Edition** Helen Baldwin, 2010-02-27 Revised and Updated 2010 with new resources and dedications In May 1997 Randy and Helen Baldwin eagerly welcomed their third child Jeffrey as did his older siblings Matthew and Katie Jeffrey's arrival unplanned but greatly anticipated sparked a few adjustments in this family long removed from diaper duty but Jeffrey was obviously a special gift Eight weeks later life took a completely unexpected downward spiral into the depths of despair when Jeffrey was diagnosed with Spinal Muscular Atrophy SMA a rare progressive genetic neuromuscular disease with deadly ramifications The neurologist handed over the utterly devastating news that Jeffrey had a severe case of the most destructive form without a morsel of hope that anything could be done to thwart the effects of the killer disease Faced with the nightmare that their baby was expected to die within two years

and that there was no treatment or cure Randy and Helen took their faith in God to a higher level and embarked on a quest to defy SMA and its stranglehold on their precious baby's life They sought the expertise of alternative practitioners and relentlessly relied on prayers for Jeffrey's health and for strength courage and wisdom for themselves and their family The Jeffrey Journey is the story of how one family with friends and family prayer and God's grace rose to the challenge of caring for a dying child as they also realized the countless blessings left by their angel

**Voices of the Chronically Ill** Mary Kalfoss, 2023-08-09 This book describes what it is like to embody chaos and liminality in living with a physical chronic illness and how these experiences are related to the loss and remaking of one's sense of self It also encourages readers to listen closely to the figurative language people use in trying to articulate the unspeakable Focusing upon a wide array of narrative fragments gathered from first person literary work and research the author portrays how a conglomerate of sensations feelings and thoughts are embodied in the illness experience The voices present in this text speak of vulnerability suffering and brokenness yet also endurance and fortitude The ethics of philosopher Emmanuel Levinas provide the grounds for offering care lovingly This book makes a significant contribution to helping students practitioners and carers understand the chaos that is inherent yet so often silenced in the illness experience This text could also be of interest to laypeople who are curious about how subjective illness is experienced and to those who are ill who may be seeking affirmation for what they are experiencing

Talking with Patients About the Personal Impact of Illness Leonore Buckley, Dennis J. Shale, 2018-04-19 This book explores the psychosocial impact of serious illness its effect on a person's identity and relationships and the doctor's role in counseling patients Even the most seasoned physician often feels inadequate when it comes to discussing the personal impact of disability and serious illness with patients It takes time attention and skill Most physicians who are good at this learn what to say from observations of physicians they respect and the conversations they share with patients over many years of practice Like everything else in medicine there is a continuous learning curve This book offers a beginning It includes first hand experiences and reflections on serious illness by physicians and patients concrete advice on how to initiate discussions of difficult psychosocial issues topics for organising discussion suggested readings and guides for patient interviews Much is written about patient centered care and the patient experience What sets this book apart is first Lenore Buckley's ability to tell stories about her own medical experience These teaching tales give young physicians a sense of the task that their profession requires of them while keeping that task within human proportions Second and complementing that is her excellent compilation of quotations and stories from the memoirs of patients and physicians especially physicians as patients I hope this empathic useful collection of materials for teaching and reflection finds its way into medical school curricula and I hope it is one of those books that physicians return to during years of practice especially when they sense that the treatment expert is crowding the witness out of the room Patients need both doctors Lenore Buckley shows how doctors are able to expect nothing less of themselves Arthur W Frank in the Foreword

Use Your Words Kate Hopper, 2012-04-02

USE YOUR WORDS introduces the art of creative nonfiction to women who want to give written expression to their lives as mothers. Written by award winning teacher and writer Kate Hopper, this book will help women find the heart of their writing, learn to use motherhood as a lens through which to write the world, and turn their motherhood stories into art. Each chapter of USE YOUR WORDS focuses on an element of craft and contains a lecture, a published essay, and writing exercises that will serve as jumping off points for the reader's own writing. Chapter topics include the importance of using concrete details, an overview of creative nonfiction as a genre, character development, voice, humor, tense, and writing the hard stuff, reflection, and back story, structure, revision, and publishing. The content of each lecture is aligned with the essay/poem in that chapter to help readers more easily grasp the elements of craft being discussed. Together, the chapters provide a unique opportunity for mother writers to learn and grow as writers. USE YOUR WORDS takes the approach that creative writing can be taught, and this underscores each chapter. When students learn to read like writers, to notice how a piece is put together, and to question the choices a writer makes, they begin to think like writers. When they learn to ground their writing in concrete sensory details and begin to understand how to create believable characters and realistic dialogue, their own writing improves. USE YOUR WORDS reflects Kate's style as a teacher, guiding the reader in a straightforward, nurturing, and passionate voice. As one student noted in a class evaluation, "Kate is a born writer and teacher, and her enthusiasm for essays about motherhood and for teaching the nuts and bolts of writing so that ordinary mothers have the tools to write their stories is a gift to the world. She is raising the value of motherhood in our society as she helps mothers build their confidence and strengthen their game as writers."

Spirituality and Meaning Making in Chronic Illness Kelly Arora, 2020-02-21. Many spiritual caregivers, including chaplains, spiritual directors, and clergy, are unaware of how they can support people with chronic health conditions. This book combines insights on chronic illness with spiritual care skills and suggestions to enhance well-being for people living with long-term illness. Using a narrative approach, the author reflects on the stories of two women: Dorothy from The Wizard of Oz, who travels from Kansas, a state of health, to Oz, an illness experience, alongside the author's personal experiences of managing an incurable autoimmune disease. Chapters will include guidelines and exercises that help equip caregivers to facilitate healing with people who live with long-term health conditions.

**Contemporary Authors** Lisa Kumar, 2004-07. A biographical and bibliographical guide to current writers in all fields, including poetry, fiction, and nonfiction, journalism, drama, television, and movies. Information is provided by the authors themselves or drawn from published interviews, feature stories, book reviews, and other materials provided by the authors/publishers.

Stories of Illness and Healing Sayantani DasGupta, Marsha Hurst, 2007. A collection of women's illness narratives. *Stories of Illness and Healing* is the first collection to place the voices of women experiencing illness alongside analytical writing from prominent scholars in the field of narrative medicine. The collection includes a variety of women's illness narratives, poetry, essays, short fiction, short drama, analyses, and transcribed oral testimonies, as well as traditional analytic essays about themes and issues raised by the

narratives *Stories of Illness and Healing* bridges the artificial divide between women's lives and scholarship in gender health and medicine. The authors of these narratives are diverse in age, ethnicity, family situation, sexual orientation, and economic status. They are doctors, patients, spouses, mothers, daughters, activists, writers, educators, and performers. The narratives serve to acknowledge that women's illness experiences are more than their diseases; that they encompass their entire lives. The pages of this book echo with personal accounts of illness, diagnosis, and treatment. They reflect the social constructions of women's bodies, their experiences of sexuality and reproduction, and their roles as professional and family caregivers. Finally, and perhaps most importantly, *Stories of Illness and Healing* draws the connection between women's suffering and advocacy for women's lives.

*The Gale Encyclopedia of Neurological Disorders* Stacey L. Chamberlin, Brigham Narins, Gale Group, 2005. Contains nearly four hundred alphabetized full-length articles on neurological disorders and drugs and treatments for neurological disorders and includes further reading lists.

**The Journey from the Center to the Page** Jeff Davis, 2008-04-01. Jeff Davis artfully illustrates how yoga philosophies and practices can be an invaluable ally to the writing life.

*Library Journal* Melvil Dewey, Richard Rogers Bowker, L. Pylodet, Charles Ammi Cutter, Bertine Emma Weston, Karl Brown, Helen E. Wessells, 2005. Includes beginning Sept 15 1954 and on the 15th of each month Sept-May a special section. School library journal ISSN 0000-0035 called Junior Libraries 1954-May 1961. Also issued separately.

**The Complete Directory for People with Chronic Illness** Sedgwick Press, 2005. This informative resource provides a comprehensive overview of the support services and information resources available for people diagnosed with a chronic illness. Thousands of hours of research have gone into this 2005-06 edition; hundreds of new entries have been added, and thousands of enhancements have been made to existing entries. This widely hailed directory is structured around the 90 most prevalent chronic illnesses, from Asthma to Cancer to Wilson's Disease, and provides a comprehensive overview of the support services and information resources available for people diagnosed with a chronic illness. Each chronic illness has its own chapter and contains a brief description in layman's language followed by important resources for National, Local, Organizations, State Agencies, Newsletters, Books, Periodicals, Libraries, Research Centers, Support Groups, Hotlines, Web Sites, and much more. Two indexes provide quick access to this wealth of information: Entry Index and Geographic Index. This directory is an important resource for health care professionals, the collections of hospital and health care libraries, as well as an invaluable tool for people with a chronic illness and their support network.

The Complete Directory for People with Disabilities Sedgwick Press, 2006.

**Library Journal**, 2005. International Business and Trade Directories Richard Gottlieb, 2003. **MLA International Bibliography of Books and Articles on the Modern Languages and Literatures**, 2008.

**Forthcoming Books** Rose Arny, 2004.

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