



Decision-Making About Newborn Screening Panels in Canada: Risk Management and Public Participation

*Marisa Beck, Brendan Frank, Sara Minaecian,
and Stuart G. Nicholls* 

NEWBORN BLOODSPOT SCREENING: AN UNDER-STUDIED RISK ISSUE

The World Health Organization defines screening as “the presumptive identification of unrecognized disease in an apparently healthy, asymptomatic population by means of tests, examinations or other procedures that can be applied rapidly and easily to the target population” (Wilson & Junger, 1968). Population-based screening programs exist for different stages of life, from prenatal screening of the developing fetus, through newborn screening, to screening of adults.

M. Beck (✉) · B. Frank
Ottawa, ON, Canada
e-mail: mpenslar@gmail.com

S. Minaecian
University of Oxford, Oxford, United Kingdom

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Decision Making And The Defective Newborn

**Alan Meisel, Kathy L.
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Neural Tube Defects Diego F. Wyszynski, 2005-10-13 Neural tube defects affect about 4000 pregnancies each year and are thus among the most common of severe birth defects Prenatal diagnosis can now detect about 70% of neural tube defects but the tests produce many false positives so the question is under what circumstances should they be recommended This comprehensive volume the collective knowledge of more than 55 experts in the field provides lucid and authoritative discussions on this topic as well as on a wide variety of theoretical experimental and clinical issues *Coping with Crisis and Handicap* Aubrey Milunsky, 2012-12-06 For over 20 years I have accepted the challenge and had the privilege of caring for sick children agonizing with their parents during periods of serious illness which were sometimes fatal Because of my particular interest in and concern about birth defects and genetic disease many of these children had severe disabling handicaps which were often genetic and included mental retardation Hence care of these children and their families was often complicated by the presence of serious or profound genetic defects The initial realization of the nature of the disorder invariably led to emotional difficulties and inevitably later spawned chronic distress For some children inexorable deterioration led to untimely deaths while the parents agonized over their handicapped chronically ill or defective but nevertheless loved **Legal Issues in Pediatrics and Adolescent Medicine** Angela Roddey Holder, 1985-01-01 This book is one of four publications intended to engage a broad range of persons in informed decision making regarding key health and human value questions Each publication has a usefulness of its own while all four comprise a convenient series

Practical Decision Making in Health Care Ethics Raymond J. Devettere, 2009-12-04 For nearly fifteen years Practical Decision Making in Health Care Ethics has offered scholars and students a highly accessible and teachable alternative to the dominant principle based theories in the field Devettere's approach is not based on an ethics of abstract obligations and duties but following Aristotle on how to live a fulfilled and happy life in short an ethics of personal well being grounded in prudence the virtue of ethical decision making This third edition is revised and updated and includes discussions of several landmark cases including the tragic stories of Terri Schiavo and Jesse Gelsinger the first death caused by genetic research Devettere addresses new topics such as partial birth abortion law embryonic stem cell research infant euthanasia in The Netherlands recent Vatican statements on feeding tubes organ donation after cardiac death new developments in artificial hearts clinical trials developed by pharmaceutical companies to market new drugs ghostwritten scientific articles published in major medical journals and controversial HIV AIDS research in Africa This edition also includes a new chapter on the latest social and political issues in American health care Devettere's engaging text relies on commonsense moral concepts and avoids academic jargon It includes a glossary of legal medical and ethical terms an index of cases and thoroughly updated bibliographic essays at the end of each chapter that offer resources for further reading It is a true classic brilliantly conceived and executed and is now even more valuable to undergraduates and graduate students medical students health

care professionals hospital ethics committees and institutional review boards and general readers interested in philosophy medicine and the rapidly changing field of health care ethics **Perinatal Neurology and Neurosurgery** R.A.

Thompson, John R. Green, Stanley D. Johnsen, 2012-12-06 This volume represents a collection of topics presented at the Tenth Annual Symposium of the Barrow Neurological Institute No attempt is made to be comprehensive but rather an attempt is made to give adequate attention to the major important topics in this field Neuro developmental biology pathophysiology and laboratory evaluation are discussed Subjects include hypoxic ischemia intraventricular hemorrhage fetal neurosurgery surgery of hydrocephalus problems of apnea ultrasound and CT imaging techniques electrodiagnosis and ethical and economic issues This volume will be of interest to neurologists and neurosurgeons in general and especially to pediatric neurologists and neurosurgeons and perinatologists Richard A Thompson M D John R Green M D Stanley D Johnsen M D vii Contents Contributors v Preface vii Acknowledgments xi CHAPTER 1 Use of Fetal Neurosurgery for Experimental Studies of Structural and Functional Brain Development in Nonhuman Primates 1 Pasko Rakic and Patricia S Goldman Rakic CHAPTER 2 Pathogenesis of Perinatal Hypoxic Ischemic Brain Damage 17 Robert C Vannucci CHAPTER 3 Current Concepts of Pathophysiology of Perinatal Intraventricular Hemorrhage 41 Jan Goddard Finegold CHAPTER 4 New Therapies for Asphyxia Neonatorum and Intraventricular Hemorrhage of the Premature 57 Gary W Goldstein CHAPTER 5 Cranial Sonography and CT of the Infant 67 Diane S Babcock ix x Contents CHAPTER 6 Cross Sectional and Longitudinal Studies of Brain Stem Auditory Evoked Potentials in High Risk Infants 85 James J Stockard Janet E Stockard and Allen Merritt CHAPTER 7 Neurosurgery in Congenital Defects Other Than Hydrocephalus 111 Hector E *Issues in Child Health and Adolescent Health* A. Baum, J. E. Singer, Jerome L. Singer, 2013-05-13 Published in 1982 *Issues in Child Health and Adolescent Health* is a valuable contribution to the field of Psychology PP **Decision Making and the Defective Newborn** Chester Allan Swinyard, 1978 **Neonatal Bioethics** John D. Lantos, 2006-05-17 Neonatal intensive care has been one of the most morally controversial areas of medicine during the last thirty years This study offers an expansive view of the abstract and practical features of neonatal medicine examining the interconnected development of four key aspects of neonatal intensive care medical advances ethical analysis legal scrutiny and econometric evaluation Tracing the recent history of neonatal ethics analyzing the notable advances and considering the many lessons to be learned the authors present neonatal medicine as a paradigm of responsible societal management of medical innovation Newborn Surgery, 2Ed Prem Puri, 2003-04-30 This book is the leading international source of reference on the surgical management of neonatal disorders It provides a comprehensive compendium of the pathophysiology investigation and management of these conditions Nearly 100 contributed chapters bring together a unique international consensus of expert opinion All modern developments inc

Ethical Issues in Neurology James L. Bernat, 2008 Written by an eminent authority from the American Academy of Neurology s Committee on Ethics Law and Humanities this book is an excellent text for all clinicians interested in ethical

decision making The book features outstanding presentations on dying and palliative care physician assisted suicide and voluntary active euthanasia medical futility and the relationship between ethics and the law New chapters in this edition discuss how clinicians resolve ethical dilemmas in practice and explore ethical issues in neuroscience research Other highlights include updated material on palliative sedation advance directives ICU withdrawal of life sustaining therapy gene therapy the very low birth weight premature infant the developmentally disabled patient informed consent organizational ethics brain death controversies and fMRI and PET studies relating to persistent vegetative state

Deciding Who Lives Renee R. Anspach, 1993 In a probing look at the reality of everyday choices in neonatal intensive care units sociologist Renee Anspach explores the life and death dilemmas that have fueled much national debate Anspach considers the roles of parents doctors nurses and bioethicists in deciding the fate of terminally ill or malformed newborns

The Costs and effectiveness of neonatal intensive care, *Withholding Treatment from Defective Newborn Children* Joseph Eliot Magnet, Eike-Henner W. Kluge, 1985 **Compelled Compassion** Arthur L. Caplan, Robert H. Blank, Janna C. Merrick, 2012-12-06 In April 1982 an infant boy was born in Bloomington Indiana with Down syndrome and a defective but surgically correctable esophagus His parents refused to consent to surgery or intravenous feeding The hospital unsuccessfully sought a court order to force treatment and appeals to higher courts also failed The child identified as Baby Doe by the news media subsequently died The events in Bloomington became the catalyst for action by the Reagan administration the courts and Congress that culminated in a federal policy that makes failure to treat newborns with disabilities a form of child neglect This book centers on the public policy aspects of withholding treatment from critically ill newborns who are disabled Specifically it deals with why the policy was enacted and what impact it has had on health care workers families and infants Some of the contributors to this book spearheaded the early debate on withholding treatment Anthony Shaw's New York Times Magazine article in 1972 was the first to address these issues in the popular press The following year he published a related article in the New England Journal of Medicine Also appearing in this same issue of NEJM was the pathbreaking study coauthored by A G M Campbell on withholding treatment in the special care nursery at Yale New Haven Hospital Each of these articles promoted much public and professional discussion

Operative Pediatric Surgery 6Ed Lewis Spitz, Arnold Coran, 2006-11-24 The sixth edition of this acclaimed operative atlas continues to provide a unique level of comprehensive detail on the full range of conditions presented in childhood including the fetus and neonate that can be treated by surgical means All chapters have been thoroughly revised and updated throughout with new line diagrams where necessary Also touching upon indications complications and non operative management Operative Pediatric Surgery remains the pre eminent operative guide to a full range of paediatric conditions

Literature Search National Library of Medicine (U.S.), 1981 **Assisted Ventilation of the Neonate** Jay P. Goldsmith, Edward Karotkin, 2016-10-24 Assisted Ventilation of the Neonate 5th Edition by Drs Jay P Goldsmith and Edward Karotkin guides you through the latest

innovations in ventilatory assistance helping you improve outcomes and quality of life in newborns With a new emphasis on non invasive ventilation and earlier extubation it covers basic concepts of pulmonary pathophysiology and offers practical guidance on both basic and advanced ventilation management strategies Access expert coverage of all aspects of neonatal pulmonary care including complications nutrition transport outcomes follow up and parental education Sharpen your diagnostic and clinical skills with case studies drawn from actual patients Find key facts fast with more than 30 quick reference appendices normal values assessment charts ICU flow charts procedure steps and other useful tools Learn how to best use assisted ventilation equipment and pharmacologic agents to prevent long term pulmonary and neurologic damage Benefit from Drs Goldsmith and Karotkin s widely acknowledged expertise in neonatology and pulmonology Incorporate the latest innovations in ventilatory strategies in your practice Gain new insight into today s hottest topics including Ventilator Associated Pneumonia Quality Improvement Ventilation of Neonates in Developing Countries and Human Interactions with Mechanical Ventilators Understand the pros and cons of non invasive ventilation and earlier extubation Avoid ventilator associated illness and injury with practical guidance in this vital area Get coverage of basic concepts and advanced neonatal ventilation management strategies in one volume Master the art of mechanical ventilation with the latest innovations in ventilatory assistance and improve outcomes and quality of life in newborns

The Right to Die Alan Meisel,Kathy L. Cerminara,Thaddeus M. Pope,2004-01-01 The Right to Die Third Edition analyzes the statutory and case law [Hot Topics in Neonatal Neurology](#) Itai Berger,2008 This book is a collection of some major topics in neonatal neurology delivering up to date data The book covers several sections in a wide variety of aspects and interests The topics include VLBW infants and developmental follow up kernicterus why is it persistent and can we make it go away drugs and cerebral blood flow in the neonatal brain neonatal EEG neurological sequelae following mechanical ventilation amplitude integrated EEG aEEG surgical treatment of post haemorrhagic hydrocephalus in the neonate perinatal head trauma and neuro trauma and ethical approach to neonatal neurological issues *Pediatric Gastrointestinal and Liver Disease E-Book* Robert Wyllie,Jeffrey S. Hyams,Marsha Kay,2020-09-24 Now with full color illustrations throughout dozens of new review questions and state of the art coverage of this fast changing area Pediatric Gastrointestinal and Liver Disease 6th Edition remains the leading text in the field You ll find definitive guidance on diagnosis and treatment from experienced editors Drs Robert Wyllie Jeffrey S Hyams and Marsha Kay as well as globally renowned contributors who share their knowledge and expertise on complex issues Features an enhanced art program with full color anatomical figures clinical photos and other illustrations throughout the text Includes a new chapter on fecal transplantation FCT covering donor and recipient screening preparation delivery follow up and safety considerations as well as investigative uses for FCT for disorders such as IBD IBS and D lactic acidosis Prepares you for certification and recertification with more than 400 board review style questions answers and rationales 30% new to this edition Includes detailed diagrams that accurately illustrate complex concepts and provide at a glance

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Reviewing **Decision Making And The Defective Newborn**: Unlocking the Spellbinding Force of Linguistics

In a fast-paced world fueled by information and interconnectivity, the spellbinding force of linguistics has acquired newfound prominence. Its capacity to evoke emotions, stimulate contemplation, and stimulate metamorphosis is actually astonishing. Within the pages of "**Decision Making And The Defective Newborn**," an enthralling opus penned by a very acclaimed wordsmith, readers embark on an immersive expedition to unravel the intricate significance of language and its indelible imprint on our lives. Throughout this assessment, we shall delve to the book is central motifs, appraise its distinctive narrative style, and gauge its overarching influence on the minds of its readers.

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