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## Introduction to Proceedings from a Conference on Newborn Screening for Nontreatable Disorders

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# INTRODUCTION TO PROCEEDINGS FROM A CONFERENCE ON NEWBORN SCREENING FOR NONTREATABLE DISORDERS

*Maxwell J. Mehlman*<sup>†</sup>

Newborn screening began in the 1960's after physician Robert Guthrie developed a screening test for PKU, an autosomal recessive metabolic disorder that can be treated effectively if detected soon after birth. Guthrie also pioneered a method for collecting and transporting on special filter paper the blood samples used for screening, known as "Guthrie cards," and he insisted that the collection and analysis of the samples be performed by state public health officials. Massachusetts adopted newborn screening on a voluntary basis in 1962, but after President Kennedy's Advisory Committee on Mental Retardation recommended mandatory screening, states began to enact newborn screening as a legal requirement. By 1973, newborn screening was compulsory in 43 states. Now it is universal.

Newborn screening was justified originally on the basis that it could detect disorders that could be successfully treated or mitigated only if caught early in life. The development of faster and cheaper technologies such as tandem mass spectrometry and microchip arrays, however, enable programs to screen for far greater numbers of disorders, including many for which no readily effective treatments presently exist. Screening for these nontreatable disorders can be beneficial, in that it could spare families years of uncertainty once symptoms emerged; alert them to be on the watch for new discoveries that could provide their children with treatment; provide children with adjunctive if not curative interventions; and facilitate participation of the children in research on their disorders. Yet some public health advocates offer an additional rationale for screening for nontreatable disorders: that it can serve as a valuable tool in family planning. One recent article explains, for example: "Arguments for considering broader benefits from the early diagnosis that only newborn screening

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can provide include ... knowledge on which to base reproductive decision-making years before a disease would be diagnosed for the affected child ....”<sup>1</sup> In short, nontreatable disorders would be included in the screening panel in part in order to discourage parents from giving birth to additional children with genetic disorders, and the authors make it clear that one reason for this is to prevent these children from becoming a burden on society.

The question is whether this would be appropriate. In virtually all states, newborn screening is compulsory. In 2005, for example, the Nebraska Supreme Court rejected a constitutional challenge to newborn screening based on religious grounds.<sup>2</sup> Government-mandated health programs are justified historically on the basis as an exercise of the state’s police power aimed at preventing the spread of contagion. On this basis, for example, the Supreme Court in 1905 sustained the constitutionality of compulsory vaccination.<sup>3</sup> But unless giving birth to a child with genetic abnormalities is regarded as “spreading disease,” it cannot be justified on this basis. Moreover, mandatory screening by the state for the purpose of preventing the birth of children with birth defects may strike some as bearing too close a resemblance to the discredited, state-sponsored eugenics programs of the early and mid-20<sup>th</sup> century. Indeed, the only constitutional precedent for it is the infamous 1927 case of *Buck v. Bell*,<sup>4</sup> in which Justice Holmes upheld the Virginia law that permitted forced sterilization of the supposedly “feeble-minded.” This law became the model for the Nazi eugenics legislation enacted by the Reichstag following Hitler’s election as Chancellor of Germany.

On May 2, 2008, the Law-Medicine Center, with funding support from the Inamori International Center for Ethics and Excellence and the Center for Genetic Research Ethics and Law, both here at Case Western Reserve University, held a workshop to consider the ethical, legal, and social issues raised by the prospect of newborn screening for nontreatable disorders. The workshop, the first of its kind, took place in conjunction with a conference on ethical, legal, and social issues in human genetics sponsored by the National Human Genome Research Institute at the National Institutes of Health. This issue of *Health Matrix* presents the papers commissioned for this workshop. The papers are by five of the leading experts in the field: Donald B. Bailey, Distinguished Fellow, RTI (Research Triangle Institute) Inter-

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<sup>1</sup> Duane Alexander (NIH) & Peter C. van Dyck (HRSA), *A Vision of the Future of Newborn Screening*, 117 PEDIATRICS S350, 352 (2006).

<sup>2</sup> *Douglas County v. Anaya*, 694 N.W.2d 601 (Neb. 2005).

<sup>3</sup> *Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

<sup>4</sup> *Buck v. Bell*, 274 U.S. 200 (1927).

national; Jeffrey R. Botkin, MD, MPH; Professor of Pediatrics, University of Utah School of Medicine; Ellen W. Clayton, MD, JD; Rosalind E. Franklin Professor of Genetics and Health Policy at Vanderbilt University; R. Rodney Howell, MD; Professor of Pediatrics, Miller School of Medicine, University of Miami, Florida; and Marvin Natowicz, MD, PhD; Pediatric Geneticist; Clinical Pathologist; Vice Chairman, Genomic Medicine Institute and Neurologist at the Cleveland Clinic.