

## The Long Term Outcomes for Premature and Low Birth Weight Infants

Advances in medical technology have greatly increased the likelihood of survival for premature and low birth weight (LBW) infants. Before the introduction of neonatal intensive care in the 1960s, LBW babies experienced higher rates of developmental delay with decreasing birth weight.<sup>1</sup> Interventions to “improve” outcomes often did more harm than good, including blindness caused by the liberal use of oxygen, deafness caused by antibiotics and brain damage related to the use of sulfa drugs. The introduction of neonatal intensive care in the 1960s greatly improved outcomes, especially for very low birth weight infants (weighing less than 3.3 lbs), and by the 1970s, 80% of survivors were reportedly free of serious disability. The introduction of therapies in the 1990s, including surfactant therapy and increased use of antenatal steroids, further increased the survival of the smallest babies.<sup>2</sup> Survival rates have stabilized since the mid 1990s, and approximately 70% of the 22,845 children born weighing less than 2.2 lbs in the United States in 2002 survived.<sup>2</sup> While advances in medical technology have saved the lives of many children, increased rates of survival have also raised questions about the long term impact of low birth weight on health and quality of life, both for the infants and their families.

Survivors of premature birth may experience a range of cognitive, psychological and physical consequences of low birth weight. Though the majority of LBW children do not experience long term consequences, this population has higher rates of health and developmental challenges than normal birth weight children.<sup>1</sup> Beyond the biological risks of low birth weight, it

BIRTH WEIGHT	% OF ALL BIRTHS <sup>3</sup>
Low birth weight: < 5.5 lbs (2500g)	8.2%
Very low birth weight: < 3.3 lbs (1500g)	1.5%

appears that even survivors who pass through infancy without severe neurodevelopmental or functional consequences may experience a number of long term adverse outcomes, including limited academic skills, poor vision, poor motor skills and other chronic health challenges, such as asthma and cerebral palsy.<sup>2</sup> The child’s risk for negative outcomes increases with decreasing birth weight or gestation, and often negative outcomes do not become apparent until the child enters the school setting.<sup>1</sup> Furthermore, children of women of low socioeconomic status are at greater risk for premature birth. There is evidence, though, that enrichment programs for LBW children may moderate the negative effects of premature birth, and these programs appear to be particularly effective for low birth weight children of lower socioeconomic status.<sup>1</sup>

Understanding the potential adverse outcomes of low birth weight requires rigorous longitudinal research following the developmental trajectories of large numbers of LBW children through childhood, adolescence, and even into adulthood, to assess the long term impacts of low birth weight. Research which has been underway since the late 1970s at Case Western Reserve University has provided a wealth of information on the complex biological, developmental and social consequences of low birth weight over the lifespan.

## Focus on Research at Case Western Reserve University



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Dr. Hack is the Director of the High Risk Follow-Up Program, which has been following multiple cohorts of low birth weight babies through to adulthood since 1973. The High Risk Follow-Up Program has resulted in the publication of over 100 articles providing detailed information on the short and long-term consequences of low birth weight and has produced valuable information on the biological, psychological and social effects of LBW on individuals and their families.

### RESEARCH SUMMARY

Understanding the potential long-term costs of caring for increasing numbers of LBW children requires thorough knowledge of potential outcomes and their impact across the life course. Though the majority of LBW children develop normally without significant consequences, LBW children are at greater risk than normal birth weight children for a number of neurosensory, cognitive, neuropsychological, behavioral, academic, health and growth problems. These challenges remain despite improvements in neonatal intensive care procedures.

Dr. Hack's research has illustrated the relationship between the potential physical consequences of low birth weight and the impact of these health challenges on children's lives (See table below).

### Taking Care of Low Birth Weight Children

Caring for a child with significant health and developmental challenges may present a significant burden for families of low birth weight infants. Chronic neurodevelopmental conditions require greater investment of parental time and energy to manage the daily functioning of a dependent child. The results of Dr. Hack's research suggest that 48% of children born weighing less than 2.2 lbs have one or more compensatory dependence need, including taking daily medications, requiring special equipment for walking or personal assistance for eating, dressing, washing and toileting. Families with lower socioeconomic status, less parental education and a history of maternal depression experienced particularly high

#### LOW BIRTH WEIGHT THROUGH THE LIFESPAN: KEY FINDINGS OF THE HIGH RISK FOLLOW-UP PROGRAM

NEUROLOGICAL ABNORMALITIES	<ul style="list-style-type: none"> <li>• Cerebral palsy, blindness, deafness and other neuromotor dysfunction are potential risks of low birth weight.</li> <li>• Though the mean IQ score of low birth weight children falls within the average range, there are higher rates of deficient and subnormal intelligence.</li> </ul>
GROWTH AND DEVELOPMENT	<ul style="list-style-type: none"> <li>• Growth attainment is generally lower than normal birth weight peers.</li> <li>• Compared to their peers, children born with low birth weight are more likely to experience functional limitations.</li> </ul>
HEALTH PROBLEMS	<ul style="list-style-type: none"> <li>• Higher rates of health problems result in more medical and surgical procedures, frequent rehospitalizations after surgery, and limitations to the activities of daily life.</li> <li>• The rates of conduct disorder, hyperactivity and attentional weakness increase with decreasing birth weight and are associated with brain injury due to low birth weight.</li> </ul>
SOCIAL EFFECTS	<ul style="list-style-type: none"> <li>• Mental or emotional delay can limit a child's ability to participate in physical activities and to play or socialize with others.</li> <li>• Health problems contribute to an increased number of days spent in bed, restricting children's activity, decreasing their school attendance, and limiting their social interactions.</li> <li>• Learning problems at school place LBW children at greater risk for grade repetition or placement in special education programs.</li> <li>• LBW teens are involved in fewer risky behaviors in adolescence, including lower rates of alcohol and marijuana use, less contact with police, and lower rates of pregnancy than normal birth weight teens.</li> </ul>
FAMILY ISSUES	<ul style="list-style-type: none"> <li>• Low birth weight has significant negative effects on families, including financial impact, increased caretaker burden, and general family burden.</li> <li>• Parents of low birth weight children exhibit higher levels of parental protection at school age than normal birth weight children.</li> </ul>

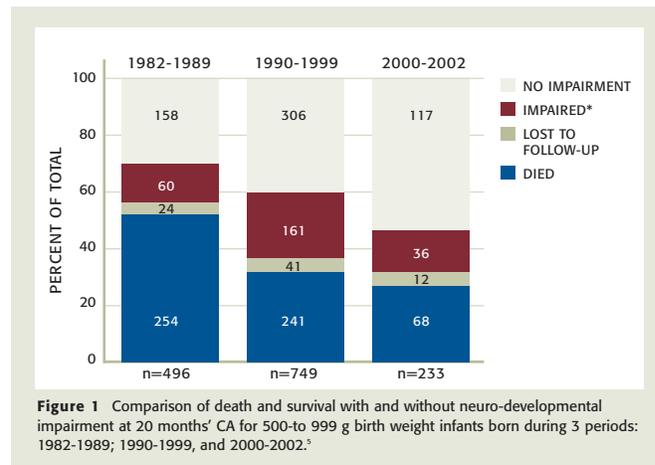
rates of impact. This illustrates the need for support for families with LBW infants with health or developmental challenges.

The increasing caretaking demands on families of LBW infants also appear to affect the parent-child relationship. Children with a variety of chronic problems are supervised and attended by their parents more closely than children without such conditions.

Increased parental protection of low birth weight children suggests effects on a child's development of autonomy and interpersonal relationships as these children enter adolescence. Increased parental protection may have positive effects in adolescence. Dr. Hack's research has shown that LBW infants are involved in fewer risky behaviors in adolescence.

### The Long-Term Effects of Low Birth Weight

Following a cohort of 242 children born weighing less than 1500g in the late 1970s, Dr. Hack found that even in adulthood, these individuals continued to have higher rates of chronic conditions attributable to neurosensory impairments and sub-normal height. Such children also had less educational attainment as young adults; their average age at high school graduation was higher, and they were enrolled in post-secondary studies at a much lower rate than normal birth weight children. The evidence of the long-term consequences of



low birth weight illustrates the need for long-term programming to mitigate the potential negative effects of low birth weight on individuals' future health and educational attainment.

### The Effects of Medical Technology on Low Birth Weight Outcomes

As technology and medical practice have changed, Dr. Hack and her colleagues have followed new cohorts of infants to examine changes in outcomes based on the technology available at the time of birth. They have compared neonatal therapies and outcomes among infants born weighing less than 1000g who were born in three periods, ranging from 1982-2002 (see figure 1). It is encouraging that in the comparison of the most recent two cohorts of infants, survival without impairment increased while survival with impairment decreased, including decreased rates of sepsis, intraventricular hemorrhage, cerebral palsy, and neurodevelopmental impairment. This trend is

likely the result of improved neonatal procedures to support infants born at increasingly low birth weight. Though this trend suggests that advances in medical technology are saving lives and reducing impairment, it is not necessarily sustainable. If increasing numbers of infants continue to be born at decreasing birth weight, advances in medical technology must keep pace with the significant health challenges of LBW infants.

The High Risk Follow-Up Program, under the leadership of Dr. Maureen Hack, has provided extensive information on the physical, psychological and social effects of low birth weight. This increased understanding of the potential consequences of LBW provides opportunities for service providers and policy makers to develop programming to address both the short and long-term needs of LBW children and their families.

#### The information about Dr. Hack's research was drawn from the following sources:

- Hack M, Klein N, Taylor H. Long-Term Developmental Outcomes of Low Birth Weight Infants. *The Future of Children*. 1995;5(1):176-196.
- Hack M, Taylor HG, Drotar D, Schluchter M, Cartar L, Andreias L, Wilson-Costello D & Klein N. Chronic Conditions, Functional Limitations, and Special Health Care Needs of School-aged Children Born with Extremely Low-Birth-Weight in the 1990s. *Journal of the American Medical Association*. 2005;294(3):318-325.
- Wightman A, Schluchter M, Drotar D, Andreias, L, Taylor HG, Klein N, Wilson-Costello D & Hack, M. Parental Protection of Extremely Low Birth Weight Children at Age 8 Years. *Journal of Behavioral Pediatrics*. 2007;28(4):317-326.
- Hack M, Flannery DJ, Schluchter M, Cartar L, Borawski E, Klein NK. Outcomes in Young Adulthood for Very-Low-Birth-Weight Infants. *The New England Journal of Medicine*. 2002;346(3):149-157.
- Wilson-Costello D, Friedman H, Minich N, Siner B, Taylor G, Schluchter M & Hack M. Improved Neurodevelopmental Outcomes for Extremely Low Birth Weight Infants 2000-2002. *Pediatrics*. 2007;119(1):37-45.

## IMPLICATIONS FOR POLICY AND PRACTICE

The findings of the High Risk Follow-Up Program are relevant for policy makers, clinicians, service providers and parents. They clearly illustrate the advances in care for low birth weight infants over the last 30 years and show that more and more low birth weight babies are surviving. However, more work remains to be done.

Low birth weight in the United States is a troublesome and persistent medical and social problem. Despite the improvement in outcomes for LBW infants, the rate of low birth weight remains high and has been rising steadily since the mid-1980s and now equals the rate reported nearly 40 years ago. The most recent data from the CDC/NCHS National Vital Statistics System<sup>3</sup> show that the rate of low birth weight was 8.2% of all births in 2005. This is 8% higher than in 2000 and 22% percent higher than in 1984.

Also of concern are persistent racial disparities. Nationally, black infants are more likely than babies of other races to be low birth weight. In 2005, 14% of non-Hispanic black infants were low birth weight, compared with 7.3% of white infants. Additionally, black infants weighting 1500 grams or less are five times less likely to survive than white infants.

Researchers and medical personnel continue to struggle with the persistent problem of low birth weight. To address it, it is very important that research into the causes of low birth weight continues, and that data on birth outcomes be continuously monitored. These efforts identify the predictors of infant mortality and morbidity. For example, we know that some groups of mothers, such as adolescents, women over 35, and mothers with a history of LBW births are more likely to give birth to a LBW infant. This type of research will provide clues as to where and to whom prevention efforts should be directed.

Primary prevention of preterm and low birth weight birth is the first goal. We know that women who have access to adequate health services before, during, and after childbirth have better outcomes and healthier children. Thus early and regular prenatal care is critical. At prenatal visits, the health of both mother and fetus is monitored. Specific attention can be given to maternal nutrition and weight gain which affect fetal weight gain and birth weight. Prenatal care also provides an opportunity to address maternal behaviors, such

as the use of alcohol, cigarettes, and illicit drugs, which contribute to poor fetal growth and other complications.

Programs and policies should be put in place to assure that all mothers have access to regular prenatal care. This requires not only expanded access to prenatal care services themselves, but also ensuring that pregnant women, and all women of child bearing age, have adequate health coverage. Women who lack health insurance are less likely to seek and obtain prenatal care. Efforts to expand eligibility for *Medicaid* and *SCHIP* (the State Children's Health Insurance Program) and to ensure that all eligible individuals are enrolled are crucial.

In those cases that low birth weight is not prevented, as Dr. Hack's research demonstrates, immediate care and treatment followed by early intervention services can greatly improve the outcomes for these children. In Ohio, programs such as *Help Me Grow* work to identify LBW children at birth and provide them and their families with needed services (for more information see: <http://www.ohiohelpmegrow.org/>).

The research presented in this brief demonstrates that much progress has been made. However, continued efforts to reduce the number of babies born with low birth weight and to improve outcomes for them will benefit not only the children themselves, but also their schools, communities and families. Dr. Hack's research contributes greatly to our understanding of the issue of low birth weight across the life course, and provides considerable insight into ways policy and practice are, or could be, used to address this issue.

<sup>1</sup> Hack M, Klein N, Taylor H. Long-term developmental outcomes of low birth weight infants. *The Future of Children*. 1995;5(1):176-196.

<sup>2</sup> Hack M, Taylor HG, Drotar D, Schluchter M, Cartar L, Andreias L, Wilson-Costello D & Klein N. Chronic conditions, functional limitations, and special health care needs of school-aged children born with extremely low-birth-weight in the 1990s. *Journal of the American Medical Association*. 2005;294(3):318-325.

<sup>3</sup> Martin JA, Hamilton BE, Sutton PD, Ventura SJ, Menacker F, Kirmeyer S, Munson ML. Births: Final data for 2005. National vital statistics reports; vol 56 no 6. Hyattsville, MD: National Center for Health Statistics. 2007.

<sup>4</sup> The Mother Child Health Federal State Partnership. *Ohio Snapshot* 2006.

<sup>5</sup> Ohio Department of Health. *Needs assessment of Ohio's maternal and child health population*. Columbus, Ohio 2006.



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