

*Hospitalization Characteristics and
Survival of Children with Down Syndrome
through Age 3*

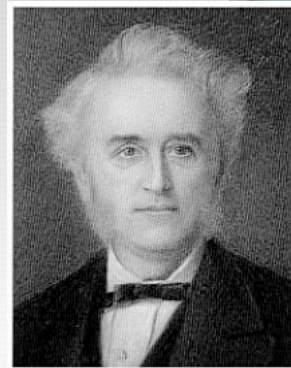
Richard C. Urbano^{1,2}, PhD & Robert M. Hodapp^{1,3}, PhD
Vanderbilt University
Vanderbilt Kennedy Center¹
Department of Pediatrics²
Department of Special Education³

Tuesday, Feb. 24th from 1:30-3:30 PM.

1

History

- J. Langdon Down, MD
(1828-1896)
- Observations on an Ethnic
Classification of Idiots,
London Hospital Reports,
3:259-262, 1866



<http://www.neonatology.org/classics/default.html>

2

History

- Jerome Lejeune
- Identified Trisomy 21 in Down syndrome 1959
- "it would take less effort to find a cure for Down syndrome than to send a man to the moon."
- Folic acid and neural tube defects
- 5p- Cri du Chat (1963)

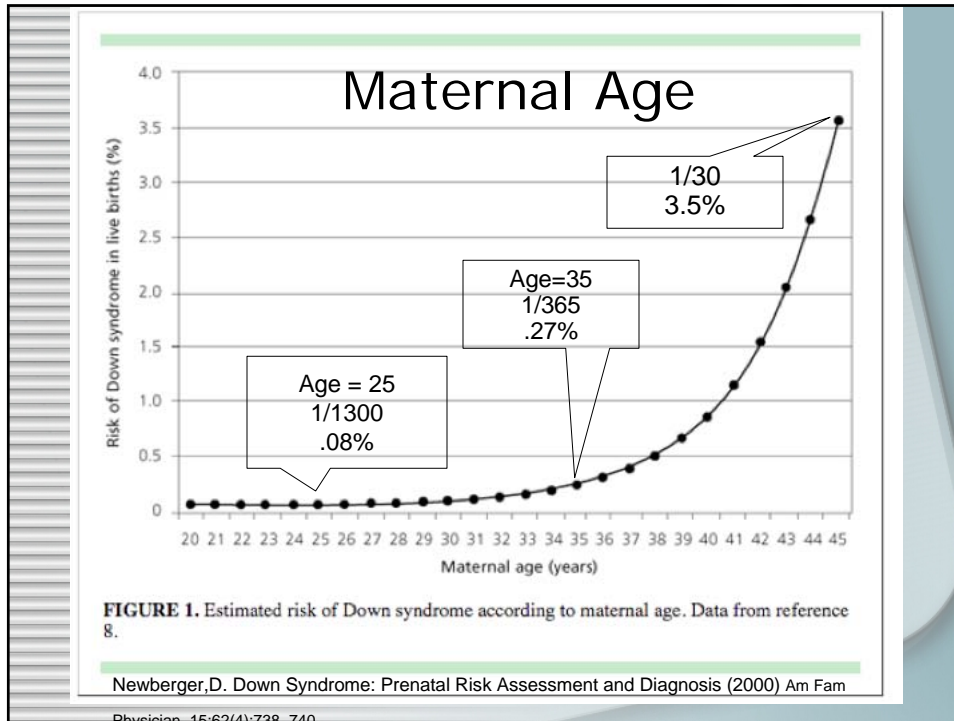


3

Over 140 years of research on Down syndrome?

- Maternal Age
- Health & Life Expectancy

4



Still true?

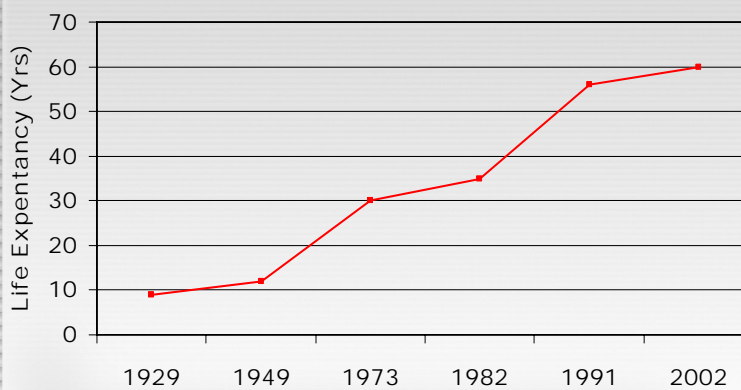
- "New era, new worry: New tests for Down syndrome could lead to more abortions and less support for families", *Newsweek*, Dec. 15, 2008
- "Is Down syndrome a disappearing birth defect?" *Journal of Pediatrics*, Jan. 2008
- Highlights how little we know about these families

Mortality

- Longer life spans from early years
 - Penrose, 1912—9 years
 - Recent studies—58-60 years

7

Increasing Life Expectancy in Down Syndrome

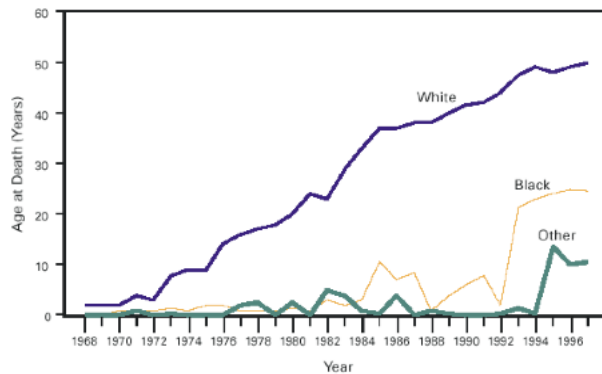


Bittles & Glasson, 2004

8

Racial Disparities in Age of Death

FIGURE 1. Median age at death of persons with Down Syndrome, by race — United States, 1968–1997



Racial Disparities in Median Age at Death of Persons with Down Syndrome -- United States, 1968-1997. (2001) MMWR 50(22), 463-465

9

Other Health Issues

- Congenital Heart Defects—40-60%
- In-patient hospitalizations within first 3 years (Frid et al., 2004)
- Infant Mortality rates—many times higher than general population

10

Our Studies

- I-Maternal-Family Characteristics
- II-Newborn-Infant Health
 - Adverse Birth Outcomes
 - Early Hospitalizations
 - Infant Mortality

11

Methodology

- Identify TN Individuals with DS
- TN Births 1990 - 2006
- Hospital Discharge Data 1997-2005
- N=1,311

12

Birth Records

- 140+ pieces of information
- Mom (Age, Race/Ethnicity, marital status, education, prior live births, inter-delivery interval)
- Infant (gender, birthweight, gestational age, APGAR, birth complications, congenital anomalies)

13

Birth Records

- Prenatal Practices (smoking, mom weight gain, number of prenatal doctor visits, month prenatal visits began)

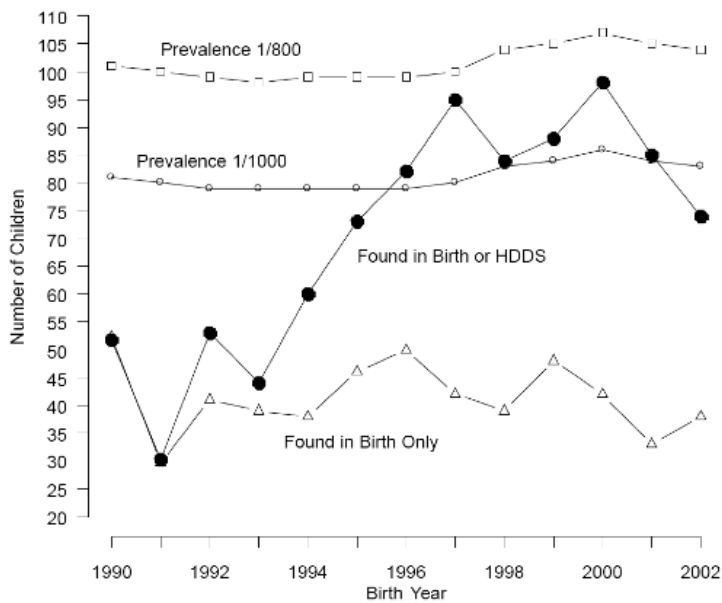
14

Hospital Discharge Records

- All inpatient and outpatient hospitalizations
- Principal and 8 secondary ICD9 diagnosis codes
- Services and procedures
- Patient address
- Hospital location

15

Expected and Observed
Number of Children with Down Syndrome



16

Death Records

- Child Age (Months, Hours, Minutes)
- Child TN Birth Certificate Number
- DOB, DOD
- Gender, Race, Ethnicity
- Underlying Cause of Death
- Multiple Cause of Death Codes

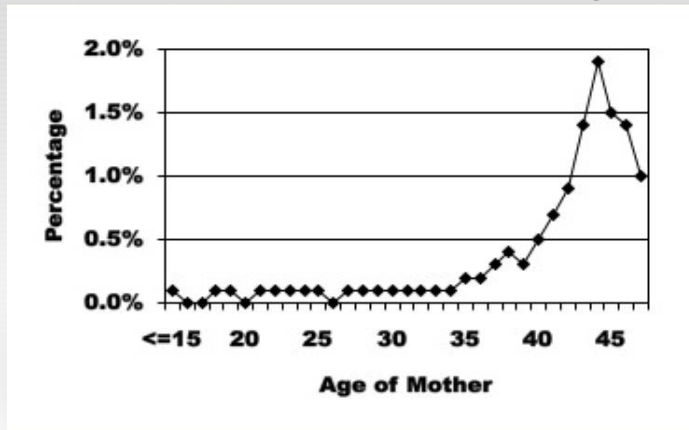
17

Findings-I: Demographics

- Demographics of Mothers of Newborns with Down syndrome, 1990-2002
 - Hodapp, Urbano, & Rosenbloom, submitted
- Demographics of African-American & White Mothers, 1990-2002
 - Hodapp & Urbano, 2008

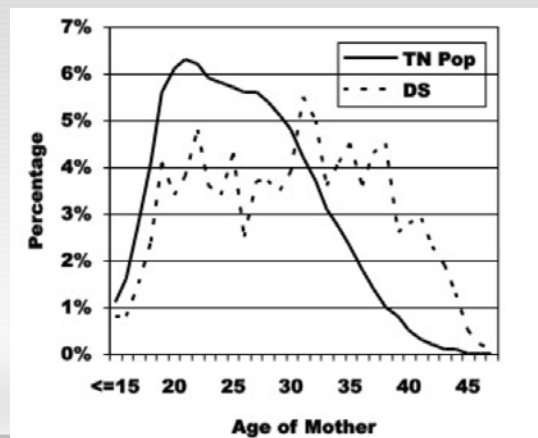
18

Percentages of DS Births at Different Maternal Ages



19

Maternal Age Distributions: TN Population v DS Births



20

Potential Racial Differences

- On average, African-American mothers give birth 2 years earlier than do Euro-American mothers
- Age at birth relates to:
 - Marital status
 - Education levels
- In other studies, maternal age, race, and education levels have all been linked to ability to know about and access services

21

Ages of Af-Am. v. White Mothers of Infants with DS

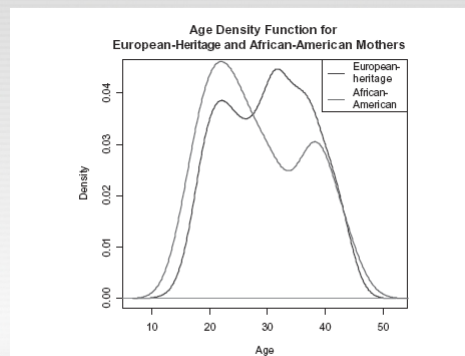


FIGURE 1
Kernel density functions by age and race.

22

TABLE 2
Educational and marital status for European-heritage vs. African-American mothers of newborns with Down syndrome

Age groups	African-American mothers				For χ^2	European-heritage mothers				For χ^2
	≤23	24-31	32-36	≥37		≤23	24-31	32-36	≥37	
<i>n</i>	54	41	14	35		165	220	169	170	
Education (Mean)	11.4	12.3	13.1	13.0		11.5	13.5	14.1	13.9	
SD	1.60	1.25	2.02	2.11	8.01*	1.50	2.15	2.23	2.57	50.343*
% Not HS graduate	44.4%	9.8%	14.3%	14.3%		34.5%	9.5%	5.9%	10.0%	
% Some college	13.0%	29.3%	50.0%	45.7%	27.53*	13.9%	52.7%	63.3%	62.4%	131.35*
Marital status %										
Married at birth	14.8%	41.5%	57.1%	57.1%	20.23*	61.8%	87.3%	92.3%	89.4%	71.13*

* $p < 0.0001$; χ^2 for Education levels = 3 (No high school, high school graduate, some college) \times 4 age levels (= 6 degrees of freedom).
HS, high school; SD, standard deviation.

23

Summary of Demographics Findings

- Mothers of children with DS continue to be older—more older, fewer younger
- Age-curves differ based on whether mother is African-American or White
- More younger mothers in African-American group
- In both groups, younger = less educated and less often married

24

Results: II-Health Issues

- A-Adverse Birth Outcomes
 - Hodapp, Urbano, & Rosenbloom, submitted
- B-Early Hospitalization
 - So, Urbano, & Hodapp, 2007
- C-Infant Mortality
 - Goldman, Urbano, & Hodapp, in preparation

25

A-Adverse Birth Outcomes

- Preterm < 37 weeks gestational age
- Low Birthweight < 2500 grams
- Small-for-gestational-age

26

Adverse Birth Outcomes

- TN resident births 1990-2005
N=1,220,717
- DS N= 1,043.

27

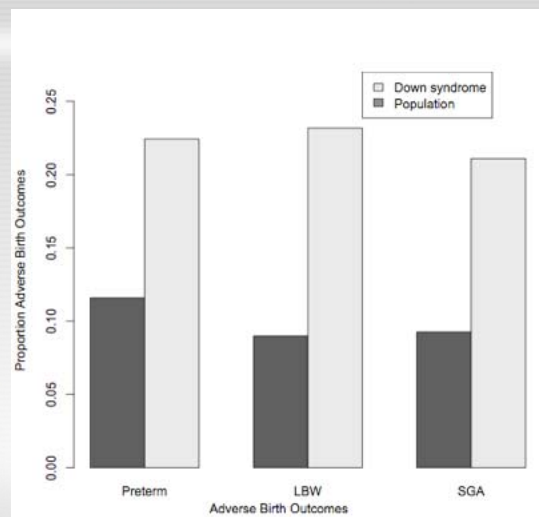


Figure 1. Proportion of Preterm, Low Birthweight and Small for Gestational Age by Group

28

Adverse Birth Outcomes

- Low birth weight
 - OR=3.1; 95%CI: 2.6-3.5
- Preterm
 - OR=2.2; 95%CI: 1.9-2.6
- Small-for-gestational age
 - OR=2.6; 95%CI: 2.3-3.1

29

Adverse Birth Outcomes

Predict ABOs Non-DS

low maternal education	maternal age
unmarried marital status	race
few prenatal visits (0 to 5)	late start of prenatal care
maternal weight gain of less than 25 pounds	maternal smoking
child gender	index child first born

30

Adverse Birth Outcomes

- Predict ABOs, DS
 - Weight Gain < 25 pounds
 - < 5 prenatal visits (for 2 of 3 ABO's)

31

B-Early Hospitalization

- Rates
- Reasons (Diagnoses)
- Congenital Heart Defects

32

Hospitalizations

- N = 212 newborns, from birth to 3
- Birth Year 1997, 1998, 1999
- Newborns with DS identified through birth hospitalization
- "Birth forward" = conservative strategy to avoid "stacking the deck" with later hospitalized infants

33

Hospitalizations

- 50% admitted at least once
- 12 (11%) hospitalized 5-9 times
- Under Age 1 rate 4 times non-DS population

34

Connections to Congenital Heart Defects

	Number of children admitted to the hospital*			
	0 times	1 time	2-4 times	5-9 times
CHD	38 (33.0%)	33 (28.7%)	33 (28.7%)	11 (9.6%)
non-CHD	69 (70.4%)	15 (15.3%)	14 (14.3%)	0 (0%)

* Excludes birth hospitalization.

35

Connections to Congenital Heart Defects

Cardiac Surgery (Dx CHD N = 112)

- 67% Hospitalized
- 36% Cardiac Surgery

36

Hospitalizations

CHD vs non-CHD

Most frequent condition: Respiratory Infections

- 65% CHD
- 71% without CHD
- Even infants with CHD are often entering hospital for pneumonia, bronchitis, and other respiratory problems

37

C-Infant Mortality in DS

- How Many:
 - Deaths per 1,000 live births
 - N = 103
- When:
 - Age of Death
 - 1st day
 - Less than 28 day
 - Less than 1 yr
- Why:
 - Causes-correlates of death

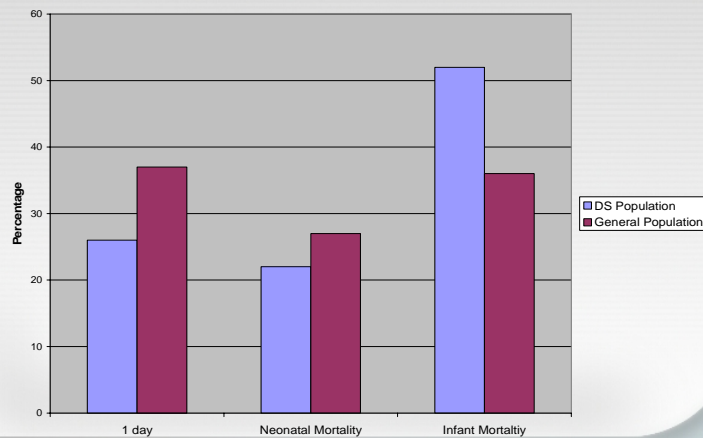
38

How many: Infant Mortality in Down syndrome

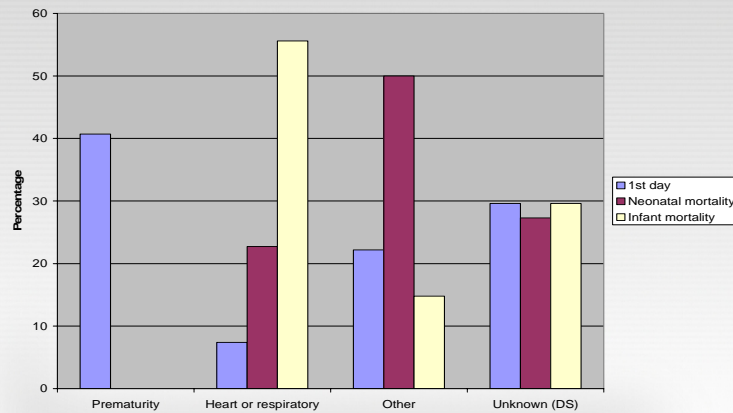
Authors and publication date	Location and years of record	Databases used	DS infant mortality rate	Population infant mortality rate	Odds ratio
Current study	Tennessee, 1990-2006	Tennessee Department of Health Birth Registry, Death Registry, and Hospitalization Records	7.9%	.87%	9.1
Shin et al. (2007)	5 counties of metropolitan Atlanta, 1979-2003	Metropolitan Atlanta Congenital Defects Program, Georgia vital records, and National Death Index	6.4% (59/922)	1.1%	5.8
Weierman et al. (2008)	The Netherlands, January 1- December 31, 2003	Dutch Pediatric Surveillance Unit, Statistics Netherland, National Dutch Neonatal Registry, National Dutch Obstetric Registry	4.0% (13/322)	0.48%	8.3
Rasmussen et al. (2006)	5 counties of metropolitan Atlanta, 1979-1998	Metropolitan Atlanta Congenital Defects Program, State of Georgia Certificate of Live Birth, National Death Index	7.1%	1.1%	6.5
Leonard et al. (2000)	Western Australia, 1980-1996	Birth Defects Registry, Maternal and Child Health Research Database	8.3%	0.5%*	16.6
Bitles et al. (2006)	Western Australia, 1953-2000	Disability Services Commission of Western Australia Database, Western Australia Cancer Registry, Western Australia Death Registry, National Death Index	6.5%	0.5%*	13.0
Mastroiacovo et al. (1992)	Italy, 1978-1992	Italian Multicentric Registry of Birth Defects	20.2%	1.4%	14.4
Sadetski et al. (1999)	Israel, 1979-1983, 1987-1991	Israeli National DS Birth Registry, National Population Registry, National Central Bureau of Statistics	24.5% (170/692)	1.0%	24.3

*General population mortality rate obtained from published sources
Goldman, Urbano, & Hodapp, in preparation.

When?: DS v. TN Population Deaths in 1st Year



Why?: Causes-Correlates



41

Summary: II-Health Issues

- Although great advances have been made in DS health care, issues remain in terms of:
 - A-Adverse Birth Outcomes
 - B-Early Hospitalizations
 - C-Mortality throughout 1st year of life

42

A-Adverse Birth Outcomes

- High levels
 - 20-25% of all DS births
 - OR's from 2.2 (preterm) – 3.1 (LBW)
 - M weight gain & (to some extent) # of prenatal visits = sole predictors
 - Many "usual" predictors do not predict

43

B-Early Hospitalizations

- Experienced by ½ of sample
 - Most before 1st birthday
 - More often in CHD infants, who often also have multiple in-patient stays
 - Often for respiratory problems

44

C-Mortality in 1st Year

- Many times more likely than in non-DS population
- More often beyond 1st month
- Early = preterm & “born too soon”
- Later = heart-respiratory

45

Lucas



46

Acknowledgements

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Samantha Goldman	Trent Rosenbloom
Meghan Burke	Stephanie So
Cole Beck	Jeremy Stephens

47

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END

48

J. L. Down Quotes

- "The hair is not black, as in the real Mongol, but of a brownish colour, straight and scanty. The face is flat and broad, and destitute of prominence. The cheeks are roundish, and extended from one another. The eyes are obliquely placed, and the internal canthi more than normally distant from one another.....The lips are large and thick with transverse fissures. The tongue is long, thick, and is much roughened. The nose is small. The skin has a slight dirty yellowish tinge, and is deficient in elasticity, giving the appearance of being too large for the body."

49

J. L. Down Quotes

- "They have considerable power of imitation, even bordering on being mimics. They are humorous, and a lively sense of the ridiculous often colours their mimicry...They are usually able to speak; the speech is thick and indistinct, but may be improved very greatly by a well-directed scheme of tongue gymnastics..."
- "...whatever advance is made intellectually in the summer, some amount of regression may be expected in the winter."

50