The March of Dimes Data Book for Policy Makers: Maternal, Infant, and Child Health in the United States 2016 provides national and state data highlighting infant mortality, birth defects, preterm and low birthweight births, health insurance, and health promotion strategies. This easy-to-use resource guide is aimed at public policy makers and others seeking quick facts at their fingertips.

Readers interested in more detail and regular updates of the data presented in this book should visit PeriStats, the March of Dimes interactive data resource at marchofdimes.org/peristats.

Except where noted, information in this Data Book is for the United States. State level data may be found at: http://www.marchofdimes.org/advocacy/data-book-for-policy-makers-maternal-and-infant-health-in-the-united-states. Where possible, data for Puerto Rico are included.

The March of Dimes Data Book for Policy Makers was produced by Nicole Garro, Cynthia Pellegrini, Lauren Viehmann, Christina Berry and Jessica Holmes of the Office of Government Affairs. Rebecca Russell, and Caroline Alter of the March of Dimes Perinatal Data Center prepared much of the data. Don Komai of Watermark Design and Chintan Parikh from Publishing Resources provided services to assist the March of Dimes with the production of the publication.

The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to support research and services related to polio. Today, the Foundation works to improve the health of women, infants, children and families by preventing birth defects, premature birth and infant mortality through research, community services, education and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with chapters in all 50 states, the District of Columbia, and Puerto Rico.

We trust this Data Book and other March of Dimes resources (available at marchofdimes.org or nacersano.org) will be helpful as we work together toward the day when every baby is born healthy.

Dr. José Cordero, Vice Chair
Mission Advancement Committee
March of Dimes Board of Trustees

Dr. Jennifer L. Howse, President
March of Dimes
About PeriStats

PeriStats, the March of Dimes interactive web resource (marchofdimes.org/peristats) offers the latest data on maternal, infant, and child health at national, state, and local levels. Users – from the general public to policy makers, researchers, providers, and students – will find the site comprehensive and easy to use.

Look for the PeriStats logo on pages throughout the Data Book for Policy Makers. It’s a signal that more detailed – and perhaps more current – information is available on the website.

Updated at least annually, PeriStats covers data for multiple years for topics like birth rates, infant mortality, prematurity, and low birthweight; tobacco, alcohol, and illicit drug use; cesarean section rates; newborn screening; and health insurance coverage. Information by race, ethnicity, and maternal age is also available for many of these indicators.

Users can compare data for cities, counties, states, and the United States and can choose various output formats, including graphs, maps, tables, and slides which they can use in reports or presentations. Together, PeriStats and the Data Book are powerful tools for helping inform policy to improve maternal, infant, and child health in the United States.
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Maternal, Infant, and Child Health Objectives for 2020

*Healthy People 2020*, a series of national health objectives to be achieved by the year 2020, was released by the U.S. Department of Health and Human Services (HHS) in December 2010. These objectives are used to measure the overall health of the United States and the impact of health promotion and disease prevention activities.

- The overarching goals of this initiative are to increase the quality and years of healthy life and eliminate disparities in health status, create social and physical environments that promote health, and promote healthy development and health behaviors across the lifespan.

- A number of the *Healthy People 2020* objectives concern maternal, infant, and child health. Among them are the measurement of efforts to:
  - Reduce rates of infant and maternal mortality, preterm and low birthweight births, and birth defects
  - Increase the proportion of women receiving early and adequate prenatal care
  - Promote healthy behaviors such as breastfeeding and abstaining from tobacco and alcohol while pregnant
  - Ensure appropriate newborn screening, follow-up testing, and treatment

- Many relevant *Healthy People 2020* objectives are included in this Data Book. More detailed information about the initiative is at the website www.healthypeople.gov.

- The March of Dimes set a national preterm birth goal of 8.1%, which is lower than the Healthy People goal of 11.4%. This ambitious goal is included in this Data Book to measure progress in improving rates of preterm birth.
March of Dimes Prematurity Campaign

The March of Dimes has established ambitious goals to reduce preterm birth rates in the U.S. to 8.1% by 2020 and 5.5% by 2030. The March of Dimes Prematurity Campaign has created a plan for achieving these goals. If successful, this campaign will result in an estimated 1.3 million fewer babies born preterm between 2014 and 2030 and an estimated associated savings of $67 billion in health and societal costs.

In its current form, the March of Dimes Roadmap focuses on seven interventions to reduce preterm birth, each of which is based on evidence of effectiveness. Other interventions will be added in the future as new evidence emerges. The seven interventions include:

- **Reducing non-medically indicated (elective) deliveries.** Inductions and caesarean sections scheduled before 39 weeks gestation without a medical reason increase the risk of early term and late preterm birth and their health consequences.

- **Increasing use of progesterone for women with a history of prior preterm birth.** Progesterone is an effective and under-utilized therapy for at-risk women.

- **Reducing tobacco use among pregnant women.** Although tobacco use is a well-documented risk factor for preterm birth and other adverse birth outcomes, many women smoke while pregnant.

- **Encouraging women to space pregnancies at least 18 months apart.** Inadequate birth spacing is a known risk factor for preterm birth.

- **Increasing use of low-dose aspirin among at-risk women to prevent preeclampsia.** Preeclampsia can threaten the life or health of both mother and baby and is a major cause of preterm birth.
Advancing interventions for women with a short cervix. Universal screening for short cervix can identify women at risk for preterm birth and increase access to interventions like progesterone therapy and cerclage.

Reducing multiple births conceived through Assisted Reproductive Technology (ART). The use of ART methods that limit the risk of multiple births can reduce the risk for preterm birth.

Achieving the March of Dimes goals will be challenging, but the benefit to America’s babies would be significant. To give every baby a fighting chance, the March of Dimes will continue to lead ambitious and sustained initiatives to avert the death and disability caused by premature birth.
On an average day in the United States...

10,926 babies are born
1,045 babies are born preterm
874 babies are born low birthweight

329 babies are born with a birth defect*
174 babies are born very preterm
153 babies are born very low birthweight

64 babies die before reaching their first birthday

* Based on Centers for Disease Control and Prevention annual estimate of at least 120,000 babies born with major structural birth defects.

Note: Numbers are approximations.

Quick stats for the United States...

- About every eight seconds, a baby is born.
- Every hour, about three babies die.
- African-American infants are more than two times as likely as white infants to die before their first birthday.
- Birth defects account for one in five infant deaths.
- Each year, about 3,000 pregnancies are affected with birth defects of the brain and spinal cord.
- About every 4½ minutes, a baby is born with a birth defect.*
- About one in ten infants is born preterm (less than 37 completed weeks gestation).
- About every 1½ minutes, a baby is born with low birthweight (less than 5½ pounds).
- Prematurity/low birthweight and related conditions account for more infant deaths than any other single cause (about 1 in 3).
- Every year, about 4,400 babies are born weighing less than one pound.
- About every two minutes, a baby is born to a teen mother.

*Based on Centers for Disease Control and Prevention annual estimate of at least 120,000 babies born with major structural birth defects.

Note: Numbers are approximations.

Infant Mortality in the United States

Even though infant mortality in the United States dropped dramatically in the past century, significant room for improvement remains.

- After remaining stable for several years, the infant mortality rate has declined nearly 12% since 2007.
- Nearly 23,500 infants died before their first birthday in 2013 – a rate of 6.0 deaths per 1,000 live births.
- In 2013, the infant mortality rate was highest in the southern region of the United States.

Infant Mortality, 1950-2013

Deaths per 1,000 live births

<table>
<thead>
<tr>
<th>Year</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1950</td>
<td>29.2</td>
</tr>
<tr>
<td>1960</td>
<td>26.0</td>
</tr>
<tr>
<td>1970</td>
<td>20.0</td>
</tr>
<tr>
<td>1980</td>
<td>12.6</td>
</tr>
<tr>
<td>1990</td>
<td>9.2</td>
</tr>
<tr>
<td>2000</td>
<td>6.9</td>
</tr>
<tr>
<td>2005</td>
<td>6.7</td>
</tr>
<tr>
<td>2006</td>
<td>6.8</td>
</tr>
<tr>
<td>2007</td>
<td>6.6</td>
</tr>
<tr>
<td>2008</td>
<td>6.4</td>
</tr>
<tr>
<td>2009</td>
<td>6.1</td>
</tr>
<tr>
<td>2010</td>
<td>6.0</td>
</tr>
<tr>
<td>2011</td>
<td>6.0</td>
</tr>
<tr>
<td>2012</td>
<td>6.0</td>
</tr>
<tr>
<td>2013</td>
<td>6.0</td>
</tr>
<tr>
<td>2020</td>
<td>6.0</td>
</tr>
</tbody>
</table>


Infant Mortality by Region, 2013

Deaths per 1,000 live births

<table>
<thead>
<tr>
<th>Region</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midwest</td>
<td>6.4</td>
</tr>
<tr>
<td>Northeast</td>
<td>5.2</td>
</tr>
<tr>
<td>South</td>
<td>6.7</td>
</tr>
<tr>
<td>West</td>
<td>4.9</td>
</tr>
</tbody>
</table>

There are considerable disparities in infant mortality rates based on race and ethnicity.

- Overall, the infant death rate for all racial groups has been reduced to 6.0 deaths per 1,000 live births, meeting one of the Healthy People 2020 objectives. However, much higher rates persist for African American infants, who are more than two times as likely as white infants to die in the first year of life.

- Among babies of non-Hispanic origin, the 2013 infant mortality rate for those born to black mothers was 11.1 per 1,000 live births, compared with 5.1 for whites, 7.6 for Native Americans, and 4.1 for Asian/Pacific Islanders.

- For Hispanics, the 2013 infant mortality rate was 5.0 per 1,000 live births. Within this group, Puerto Rican mothers had the highest rate of 5.9 per 1,000 live births.

Infant Mortality, by Race/Ethnicity of Mother, 2013

Deaths per 1,000 live births

<table>
<thead>
<tr>
<th></th>
<th>Deaths per 1,000 live births</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic*</td>
<td>5.0</td>
</tr>
<tr>
<td>White</td>
<td>5.1</td>
</tr>
<tr>
<td>Black</td>
<td>11.1</td>
</tr>
<tr>
<td>Native American</td>
<td>7.6</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>4.1</td>
</tr>
<tr>
<td>Total</td>
<td>6.0</td>
</tr>
</tbody>
</table>

* Individuals of Hispanic origin may be of any race; the racial categories in this chart (white, black, Native American and Asian/Pacific Islander) are all non-Hispanic.


Infant Mortality, by Hispanic Ethnicity of Mother, 2013

Deaths per 1,000 live births

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Deaths per 1,000 live births</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mexican</td>
<td>4.9</td>
</tr>
<tr>
<td>Puerto Rican</td>
<td>5.9</td>
</tr>
<tr>
<td>Cuban</td>
<td>3.0</td>
</tr>
<tr>
<td>Central and South American</td>
<td>4.3</td>
</tr>
<tr>
<td>Total Hispanic</td>
<td>5.0</td>
</tr>
</tbody>
</table>

For more than 20 years, birth defects have been the leading cause of infant mortality (death in the first year of life). By contrast, prematurity/low birthweight is the most common cause of neonatal mortality (death in the first month of life).

- Birth defects and prematurity/low birthweight together were responsible for 38% of all infant deaths and 47% of all neonatal deaths in 2013.

- Birth defects alone were responsible for 20% of infant deaths in 2013.

- When causes of death related to preterm birth are grouped together, preterm-related causes account for more than one third (36.3%) of infant deaths and are responsible for more infant deaths than any other single cause.

- In 2013, the leading cause of infant death differed by race. Among non-Hispanic whites, the leading cause of infant death was birth defects. Among non-Hispanic blacks, the leading cause of infant death was prematurity/low birthweight.

- The rate of death due to prematurity/low birthweight for non-Hispanic black infants was more than three times that for non-Hispanic white infants (260.7 per 100,000 versus 74.4 per 100,000 live births.)

## Leading Causes of Neonatal and Infant Mortality, 2013

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<th>Condition</th>
<th>Percent of Neonatal Deaths</th>
<th>Percent of Infant Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prematurity/Low Birthweight</td>
<td>25.9</td>
<td>18.0</td>
</tr>
<tr>
<td>Birth Defects</td>
<td>21.3</td>
<td>20.4</td>
</tr>
<tr>
<td>Maternal Complications</td>
<td>10.0</td>
<td>6.0</td>
</tr>
<tr>
<td>Placenta/Cord Complications</td>
<td>5.9</td>
<td>4.1</td>
</tr>
<tr>
<td>Bacterial Sepsis of Newborn</td>
<td>3.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Respiratory Distress Syndrome</td>
<td>3.2</td>
<td>2.0</td>
</tr>
<tr>
<td>Sudden Infant Death Syndrome (SIDS)</td>
<td>0.9</td>
<td>6.7</td>
</tr>
<tr>
<td>Unintentional Injuries (&quot;accidents&quot;)</td>
<td>0.8</td>
<td>4.9</td>
</tr>
</tbody>
</table>

**Note:** Neonatal death occurs in the first month of life (28 days). Infant death occurs during the first year of life.

After a period of marked decline, the rate of maternal mortality in the United States has increased since the 1980s.

- There were 17.8 maternal deaths per 100,000 live births in 2011, according to vital statistics data. This figure may be an undercount, however, as vital statistics data are known to underestimate maternal deaths. Reporting of maternal deaths has been improved with the 2003 revision of the death certificate.

- There are significant racial disparities in maternal mortality. In 2012, the maternal mortality rate was 11.8 per 100,000 live births for non-Hispanic white women, compared with 41.1 per 100,000 live births in non-Hispanic black women.

- Further reductions in maternal mortality are possible, given that the World Health Organization estimates that 46 countries have achieved lower maternal mortality levels than the United States in 2015.

- Experts estimate that up to half of all maternal deaths in the US could be prevented through a variety of interventions, including early diagnosis and appropriate medical care for pregnancy complications.

- One Healthy People 2020 objective is to lower the maternal mortality rate to 11.4 per 100,000 live births (from 12.7 deaths per 100,000 live births in 2007). In 2012, the CDC reported the maternal death rate was 15.9 per 100,000 live births.


Pregnancy-related mortality ratio

Note: Numbers of pregnancy-related deaths per 100,000 live births per year.

Source: Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, 2016.
Incidence of Birth Defects

Each year, an estimated 120,000 babies are born with major structural birth defects. One in five infant deaths is due to birth defects, making them a leading cause of infant mortality.

- In addition to being a leading cause of infant death (during the first year of life) birth defects rank second in leading causes of death among children ages 1-4, second among children ages 5-9, and fifth among children ages 10-14.

- Birth defects of the heart and circulatory system are the most common, affecting roughly one percent of newborns.

- Hospital costs for stays due to birth defects totaled over $4.4 billion for all birth defects and all ages in 2013. More than half of all hospital costs were related to cardiac and circulatory birth defects. In 2013, a birth defect hospital admission averaged $34,662.

- Severe birth defects may require special lifelong medical treatment. Because many conditions cannot be fully corrected, birth defects are a major cause of childhood and adult disability.

## Hospital Costs of Birth Defects, 2013

<table>
<thead>
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<th>Principal Diagnosis</th>
<th>Total number of discharges</th>
<th>Mean Costs</th>
<th>Aggregate Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac and circulatory congenital anomalies</td>
<td>39,795</td>
<td>$58,436</td>
<td>$2,311,026,228</td>
</tr>
<tr>
<td>Digestive congenital anomalies</td>
<td>18,595</td>
<td>$23,045</td>
<td>$424,988,805</td>
</tr>
<tr>
<td>Genitourinary congenital anomalies</td>
<td>9,755</td>
<td>$17,191</td>
<td>$166,042,455</td>
</tr>
<tr>
<td>Nervous system congenital anomalies</td>
<td>8,430</td>
<td>$22,117</td>
<td>$185,867,222</td>
</tr>
<tr>
<td>Other congenital anomalies</td>
<td>51,435</td>
<td>$25,838</td>
<td>$1,320,472,184</td>
</tr>
<tr>
<td>All Birth Defects</td>
<td>128,010</td>
<td>$34,662</td>
<td>$4,408,396,893</td>
</tr>
</tbody>
</table>

Source: Infant deaths from the National Center for Health Statistics, 2012-2013 period linked birth/infant death data. Weighted national estimates from HCUP National Inpatient Sample (NIS), 2013, Agency for Healthcare Research and Quality (AHRQ), based on data collected by individual States and provided to AHRQ by the States. Weighted national estimates for children 0-17 years from HCUP Inpatient Database, 2013, Agency for Healthcare Research and Quality (AHRQ), based on data collected by individual States and provided to AHRQ by the States. Downloaded 1/11/2016 from hcup.net.
States play a vital role in preventing birth defects by maintaining birth defects monitoring programs, which can detect birth defects trends and suggest areas for further research. Many also link families to needed services.

The Centers for Disease Control and Prevention (CDC) works through the states to collect data, operate research centers, and furnish information to the public on birth defects. These efforts are managed by the National Center on Birth Defects and Developmental Disabilities.

- The majority of states (42) plus Puerto Rico have some type of birth defects monitoring program, while three other states are planning one. CDC has given 13 states grants to develop or enhance their programs and to use the data they collect for prevention and referral activities.

- CDC funds six Centers for Birth Defects Research and Prevention to collaborate on major multi-state studies of birth defects. The centers are located in Arkansas, California, Iowa, Massachusetts, New York, and North Carolina. CDC also participates as the seventh study site. The researchers at these centers have a unique opportunity to examine the effects of genetics and the environment on birth defects.

- CDC works with the National Birth Defects Prevention Network to compile state data. Since state methods and data sources vary, the Network has developed guidelines to make information more comparable across states. In addition, the Network developed national prevalence estimates for 21 birth defects. Estimates of birth defects in states with monitoring programs may be found at: www.marchofdimes.org/peristats.

Sources: Centers for Disease Control and Prevention, 2016.
Organizational Location of Birth Defects Programs, 2015 (n=43)

Funding Sources for Birth Defects Programs, 2015

Source: Centers for Disease Control and Prevention, 2016.
Newborn Screening

Many inherited disorders can be identified shortly after birth through newborn screening. Early identification and treatment can help to prevent disability and, in some cases, death.

- Most tests are performed using a simple “heel stick” blood sample collected before the newborn leaves the hospital.

- The federal Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children endorsed a 2005 report by the American College of Medical Genetics that recommended screening all newborns for 29 specific conditions, which has since been updated to include 34 conditions. Categories of conditions covered include metabolic disorders, hearing impairment, and others. (See full list on page 65)

- Since 2005, five conditions have been added to the Recommended Uniform Screening Panel: Severe combined Immunodeficiency (SCID), Critical Congenital Heart Disease, Pompe Disease, Mucopolysaccharidosis 1 (MPS 1), and X-linked adrenoleukodystrophy (X-ALD).

- Financing of newborn screening programs varies by state. In some cases, states provide screening free of charge for all families. The Affordable Care Act requires all insurers to cover newborn screening costs without cost-sharing if states levy fees on families. After screening, treatment costs vary depending on insurance status and type.

### State Newborn Screening Requirements, 2016
#### A Summary

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of States Screening All Newborns^a</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amino Acid Metabolism Disorders</strong></td>
<td></td>
</tr>
<tr>
<td>Argininosuccinic acidemia</td>
<td>52</td>
</tr>
<tr>
<td>Citrullinemia type 1</td>
<td>52</td>
</tr>
<tr>
<td>Homocystinuria</td>
<td>52</td>
</tr>
<tr>
<td>Maple syrup urine disease</td>
<td>52</td>
</tr>
<tr>
<td>Phenylketonuria/hyperphenylalaninemia (PKU)</td>
<td>52</td>
</tr>
<tr>
<td>Tyrosinemia type 1</td>
<td>52</td>
</tr>
<tr>
<td><strong>Organic Acid Metabolism Disorders</strong></td>
<td></td>
</tr>
<tr>
<td>Hydroxymethylglutaric aciduria</td>
<td>52</td>
</tr>
<tr>
<td>Beta ketothiolase</td>
<td>52</td>
</tr>
<tr>
<td>Glutaric acidemia type 1</td>
<td>52</td>
</tr>
<tr>
<td>Isovaleric acidemia</td>
<td>52</td>
</tr>
<tr>
<td>Methylmalonic acidemia (cblA and cblB forms)</td>
<td>51</td>
</tr>
<tr>
<td>Methylmalonic acidemia (due to mutase deficiency)</td>
<td>52</td>
</tr>
<tr>
<td>Propionic acidemia</td>
<td>52</td>
</tr>
<tr>
<td>Multiple carboxylase</td>
<td>48 (4^b)</td>
</tr>
<tr>
<td>3-Methylcrotonyl-CoA carboxylase</td>
<td>47 (5^b)</td>
</tr>
<tr>
<td><strong>Fatty Acid Oxidation Disorders</strong></td>
<td></td>
</tr>
<tr>
<td>Long-chain L-3-hydroxyacyl-CoA dehydrogenase</td>
<td>52</td>
</tr>
<tr>
<td>Medium-chain acyl-CoA dehydrogenase</td>
<td>52</td>
</tr>
<tr>
<td>Very long-chain acyl-CoA dehydrogenase</td>
<td>52</td>
</tr>
<tr>
<td>Carnitine uptake defect</td>
<td>52</td>
</tr>
<tr>
<td>Trifunctional protein deficiency</td>
<td>48 (4^b)</td>
</tr>
<tr>
<td><strong>Hemoglobinopathies</strong></td>
<td></td>
</tr>
<tr>
<td>S/Beta-thalassemia</td>
<td>52</td>
</tr>
<tr>
<td>Sickle cell anemia</td>
<td>52</td>
</tr>
<tr>
<td>Sickle-C disease</td>
<td>52</td>
</tr>
<tr>
<td><strong>Lysosomal Storage Disorders</strong></td>
<td></td>
</tr>
<tr>
<td>Pompe disease</td>
<td>5</td>
</tr>
<tr>
<td>Mucopolysaccharidosis 1</td>
<td>4</td>
</tr>
<tr>
<td>X-linked Adrenoleukodystrophy</td>
<td>1</td>
</tr>
<tr>
<td><strong>Other Disorders</strong></td>
<td></td>
</tr>
<tr>
<td>Biotinidase deficiency</td>
<td>0</td>
</tr>
<tr>
<td>Congenital adrenal hyperplasia</td>
<td>52</td>
</tr>
<tr>
<td>Congenital hypothyroidism</td>
<td>52</td>
</tr>
<tr>
<td>Cystic fibrosis</td>
<td>51</td>
</tr>
<tr>
<td>transferase deficient galactosemia (classical)</td>
<td>52</td>
</tr>
<tr>
<td>Hearing screening</td>
<td>51</td>
</tr>
<tr>
<td>Severe Combined Immunodeficiency</td>
<td>37</td>
</tr>
<tr>
<td>Critical Congenital Heart Disease</td>
<td>44</td>
</tr>
</tbody>
</table>

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^a Testing is universally required by law or rule and fully implemented as of December, 2015 among 50 states, Washington DC, and Puerto Rico.

^b Likely to be detected and reported due to universal screening of another disorder.

For more information on the uniform panel of 34 disorders, see the August 2004 report – Newborn Screening: Toward a Uniform Screening Panel and System – developed by the American College of Medical Genetics.

Newborn Screening: Categories of Disorders

In its 2005 report to the federal Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, the American College of Medical Genetics (ACMG) recommended screening all newborns for 29 disorders for which effective treatment is available. During screening for those 29 disorders, information can be obtained for an additional 25 disorders for which no treatment is available, but of which parents should also be informed. Since the original ACMG report, five additional disorders have been added to the screening panel: Severe Combined Immunodeficiency Disorder, Critical Congenital Heart Disease, Pompe Disease, MPS 1, and X-ALD. The disorders fall into the following six general categories.

- **Amino Acid Metabolism Disorders**: This is a diverse group of disorders, with varying degrees of severity. Some affected individuals lack enzymes that break down amino acids, the building blocks of protein. In others, deficiencies exist in enzymes that help the body eliminate the nitrogen in amino acid molecules. Toxic levels of amino acids or ammonia can build up in the body, causing a variety of signs and symptoms, or even death.

- **Organic Acid Metabolism Disorders**: Diseases in this group result from the loss of activity of enzymes that help break down amino acids and other substances, such as lipids, sugars, and steroids. As a result, toxic acids build up in the body. Without dietary treatment and prevention of acute episodes, these disorders can result in coma and death during the first month of life.

- **Fatty Acid Oxidation Disorders**: Inherited defects in enzymes needed to convert fat into energy characterize disorders in the group. When the body runs out of glucose (sugar), it normally breaks down fat to support production of alternate fuels (ketones) in the liver. But this pathway is blocked in people
with these disorders. When their bodies exhaust available glucose — usually when they are ill or skip meals — their cells suffer an “energy crisis.” Without treatment, the brain and many organs can be affected, sometimes resulting in coma and death.

- **Hemoglobinopathies:** Inherited diseases of red blood cells result in varying degrees of anemia (shortage of red blood cells), serious infection, pain, and damage to vital organs. The symptoms are caused by abnormal types or amounts (or both) of hemoglobin, the main protein in red blood cells that carries oxygen from the lungs to every part of the body. In sickling disorders, an abnormal hemoglobin called HbS can cause some red blood cells to become stiff and abnormally shaped. The stiffer red blood cells can obstruct tiny blood vessels, causing pain and sometimes organ damage.

- **Lysosomal storage disorders:** Inherited disorders characterized by the accumulation of undigested or partially digested macromolecules due to missing or malfunctioning enzymes that normally break down items for reuse in the cells. The resulting buildup in the lysosomes can become toxic and eventually lead to damage to cells and organs.

- **Other disorders:** This mixed group of disorders includes some diseases that are inherited and others that are not genetic. They vary greatly in severity, from mild to life-threatening.

Note: Descriptions of the 34 disorders appear on page 65.
Preterm and Low Birthweight Births
In 2014, more than 381,000 babies were born prematurely (preterm), facing a much higher risk of health problems and death than other newborns.

- About one in ten infants is born preterm. After decades of increases, the preterm birth rate has started to decline in recent years. In 2014, 9.6% of births were preterm. The March of Dimes has established a goal to reduce preterm birth to 8.1% by 2020.

- Premature infants are almost 20 times as likely as other infants to die in the first year of life.

- Late preterm babies comprised 71.3% of all preterm births in 2014. Late preterm birth accounted for most of the increase in preterm birth rates over the past two decades, and reduction in the rate of late preterm birth is responsible for the majority of the reduction in preterm birth in recent years.

- More than 63,000 babies were born very preterm in 2014. These babies were 74 times as likely as those not born preterm to die in the first year of life.

- Premature babies who survive may suffer lifelong consequences, such as developmental disabilities, blindness, chronic lung disease, and cerebral palsy.

- There is evidence that early term infants have increased morbidity and mortality compared to infants born full term. In 2014, 24.8% of all births were early term.

Sources: Impact of late preterm birth on rising preterm birth rates from Davidoff and others, 2006. All other data from the National Center for Health Statistics, 2014 Final Birth Data and 2013 linked birth/infant death data, prepared by the March of Dimes Perinatal Data Center, 2016.
Preterm and Very Preterm Births, 1981-2014

Percent of live births

*2014 data based on obstetric estimate (OE) of gestational age; all previous years based on last menstrual period (LMP).


A FULL TERM BIRTH OCCURS AT 39 THROUGH 40 COMPLETED WEEKS GESTATION (40 WEEKS, 6 DAYS).

AN EARLY TERM BIRTH OCCURS AT 37 THROUGH 38 COMPLETED WEEKS GESTATION.

A PRETERM BIRTH OCCURS BEFORE 37 COMPLETED WEEKS GESTATION.

A LATE PRETERM BIRTH OCCURS AT 34 THROUGH 36 COMPLETED WEEKS GESTATION.

A MODERATELY PRETERM BIRTH OCCURS AT 32 THROUGH 33 WEEKS COMPLETED WEEKS GESTATION.

A VERY PRETERM BIRTH OCCURS BEFORE 32 COMPLETED WEEKS GESTATION.
Early Elective Deliveries

Elective deliveries prior to 39 weeks that are not medically necessary are associated with increased morbidity for newborn infants, longer and more costly maternity stays, and increased admissions to the neonatal intensive care unit (NICU). The March of Dimes and others have implemented various quality improvement and health education initiatives aimed at reducing the number of early elective deliveries.

- “Healthy Babies are Worth the Wait” is a multi-faceted, community-based March of Dimes health education campaign aimed at providers and mothers to promote the message that early elective deliveries put the infant’s and mother’s health at risk.

- Numerous health systems, individual hospitals and payers have implemented policies to reduce early elective deliveries. Examples of these polices include revised payment incentives and implementation of scheduling rules such as “hard stops” where elective deliveries may not be scheduled prior to 39 weeks of gestation without review by senior obstetrics staff.

- March of Dimes, the California Maternal Quality Care Collaborative, and the California Department of Health’s Maternal, Child and Adolescent Health Division collaborated on the development of a quality improvement toolkit entitled, “Elimination of Non-medically Indicated (Elective) Deliveries Before 39 Weeks Gestational Age,” which provides background information, quality improvement implementation guidelines, tools for tracking progress, and educational tools for clinicians and patient education. (for more, see prematurityprevention.org)

- Since 2006, there has been a marked decrease in early term and preterm births.
Distribution of Birth by Gestational Age, 2014

Percent of live births

30-40 weeks (Term) 58.7%

41 weeks (Late Term) 6.5%
42 weeks (Post Term) 0.4%
Less than 37 weeks (Preterm) 9.6%

37-38 weeks (Early Term) 24.8%

34-36 weeks (Late Preterm) 71.3%

Many infants born too soon are also born too small. Nearly 58% of babies born preterm in 2014 were also born low birthweight, and more than 69% of low birthweight babies were preterm.

- About one in 13 infants is born low birthweight, a rate that has declined 3% in the past eight years (from a high of 8.3% in 2006 to 8.0% in 2014).
- Nearly 56,000 babies were born very low birthweight in 2014, accounting for 1.4% of live births.
- Advances in newborn medical care have greatly reduced the number of deaths associated with low birthweight. However, a small percentage of survivors face long-term health consequences, such as intellectual disabilities, learning problems, cerebral palsy and vision and hearing loss.

Low and Very Low Birthweight Births, 2002-2014

Source: National Center for Health Statistics, 2014 final natality data. Prepared by the March of Dimes
Perinatal Data Center; 2016.
Risk of Preterm Birth

While the causes for half of preterm births are unknown, certain factors are associated with increased risk.

- Maternal age plays a role in increased risk for preterm birth, with higher preterm birth rates found among the youngest and oldest mothers. In 2014, more than 10% of births to adolescents under 18 and 14% of births to women age 40 and older were preterm.

- Multiple births also increase the risk for prematurity. In 2014, babies born in multiple births were nearly eight times as likely to be born preterm as singleton babies. Nearly 59% of twins and 98% of triplets and higher-order births were preterm. A rise in the rate of multiple births, which are associated with older age at childbearing and greater use of assisted reproductive technologies and fertility drugs, has contributed to the increase in the preterm birth rate.

- Women who have had one preterm delivery are at greater risk of having another.

- Other risk factors for preterm birth include certain infections, smoking, illicit drug use, extremes of maternal weight (obesity and underweight), and stress.

- The rise in preterm birth from the early 1980s to recent years has been linked to rising rates of early induction of labor and cesarean sections. Increases in preterm singleton birth between 1990s and 2006 have been shown to be associated with cesarean delivery; the largest percentage increase occurred among late preterm births.

Note: A singleton is defined as an offspring born alone.

Sources: Data on increase among cesarean deliveries from Bettegowda and others, 2008 and Dorman and others, 2010. All other data from National Center for Health Statistics, 2014 final natality data. Prepared by the March of Dimes Perinatal Data Center, 2016.
Preterm and Very Preterm Births, by Age of Mother, 2014


Preterm Births: Singleton, Twin, and Higher Order Multiples, 2014

Significant disparities in rates of preterm birth exist based on race/ethnicity.

- Prematurity and low birthweight together comprise the leading cause of death for African-American infants.

- African-American infants are about one and a half times as likely as white infants to be born preterm. In 2014, 13.2% of infants born to non-Hispanic black mothers were preterm, compared with 8.9% of infants born to non-Hispanic white mothers.

- Infants born to non-Hispanic black mothers were nearly two and a half times as likely as those born to non-Hispanic white mothers to be very preterm – 3.1% of births to black women, compared with 1.3% of births to white women.

- Overall, 9.0% of infants born to Hispanic women were preterm. Among Hispanics, the rate was highest for babies born to mothers of Puerto Rican descent (11.0% in 2014).

Preterm and Very Preterm Births, by Mother’s Race/Ethnicity, 2014

Percent of live births

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Moderately and Late Preterm</th>
<th>Very Preterm</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>8.9</td>
<td>13.2</td>
</tr>
<tr>
<td>Black</td>
<td>13.2</td>
<td>8.9</td>
</tr>
<tr>
<td>Native American</td>
<td>8.4</td>
<td>10.4</td>
</tr>
<tr>
<td>Asian</td>
<td>9.6</td>
<td>8.4</td>
</tr>
<tr>
<td>Hispanic</td>
<td>9.6</td>
<td>9.0</td>
</tr>
<tr>
<td>Total</td>
<td>9.6</td>
<td>9.6</td>
</tr>
</tbody>
</table>

Note: All other race categories exclude Hispanics.


Preterm and Very Preterm Births, by Hispanic Ethnicity of Mother, 2014

Percent of live births

<table>
<thead>
<tr>
<th>Hispanic Ethnicity</th>
<th>Moderately and Late Preterm</th>
<th>Very Preterm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mexican</td>
<td>8.8</td>
<td>11.0</td>
</tr>
<tr>
<td>Puerto Rican</td>
<td>11.0</td>
<td>8.8</td>
</tr>
<tr>
<td>Cuban</td>
<td>9.0</td>
<td>9.0</td>
</tr>
<tr>
<td>Central or South American</td>
<td>8.5</td>
<td>9.0</td>
</tr>
<tr>
<td>Other Hispanic</td>
<td>9.6</td>
<td>9.6</td>
</tr>
<tr>
<td>Total Hispanic</td>
<td>9.0</td>
<td>9.0</td>
</tr>
</tbody>
</table>

In 2005, the annual societal economic cost associated with preterm birth in the United States was estimated to be at least $26.2 billion. In addition to the toll of human suffering and family stress, this represents a significant burden in costs associated with medical bills, educational costs and lost productivity.

- Average first-year medical costs, including both inpatient and outpatient care, were about 10 times greater for preterm ($32,325) than for term infants ($3,325) in 2005.

- Employers pay 12 times more in health care costs for babies who are born premature/low birthweight compared to babies without complications ($54,149 versus $4,389).

- The average length of hospital stay in 2005 was 9 times as long for a preterm infant (13 days) as for an infant born at term (1.5 days).

- In 2013, four of the ten most expensive hospital stays, regardless of age, are related to infant care: infant respiratory distress syndrome, prematurity/low birthweight, cardiac/circulatory birth defects, and lack of oxygen in infants.

- Costs associated with prematurity and low birthweight are not limited to the hospital stay at birth.

- Prematurity may result in long-term physical and developmental disabilities, which generate additional costs. Children born prematurely are at greater risk of lower cognitive test scores and behavioral problems, and are more likely to be enrolled in special education classes than children born full term.

### Conditions with the Highest Inpatient Hospital Costs, 2013

<table>
<thead>
<tr>
<th>Rank</th>
<th>Principal Diagnosis</th>
<th>Mean Costs(^a)</th>
<th>Mean Length of Stay (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Infant respiratory distress syndrome</td>
<td>$67,692</td>
<td>29.3</td>
</tr>
<tr>
<td>2</td>
<td>Premature birth and low birthweight</td>
<td>$63,437</td>
<td>28.8</td>
</tr>
<tr>
<td>3</td>
<td>Cardiac and circulatory birth defects</td>
<td>$58,436</td>
<td>10.7</td>
</tr>
<tr>
<td>4</td>
<td>Leukemia (cancer of blood)</td>
<td>$52,216</td>
<td>16.0</td>
</tr>
<tr>
<td>5</td>
<td>Spinal cord injury</td>
<td>$48,544</td>
<td>12.1</td>
</tr>
<tr>
<td>6</td>
<td>Intrauterine hypoxia and birth asphyxia (lack of oxygen to baby in uterus or during birth)</td>
<td>$48,230</td>
<td>14.7</td>
</tr>
<tr>
<td>7</td>
<td>Immunity disorders</td>
<td>$42,523</td>
<td>12.3</td>
</tr>
<tr>
<td>8</td>
<td>Heart valve disorders</td>
<td>$41,950</td>
<td>8.2</td>
</tr>
<tr>
<td>9</td>
<td>Hodgkin’s disease</td>
<td>$36,196</td>
<td>11.3</td>
</tr>
<tr>
<td>10</td>
<td>Aneurysm (ballooning or rupture of an artery)</td>
<td>$33,664</td>
<td>5.5</td>
</tr>
</tbody>
</table>

\(^a\) Costs are for acute hospital care and do not include physician and other professional fees, rehabilitation expenses, or costs associated with follow-up care or home care.

Women who receive prenatal care are more likely to have access to preventive services such as screening and diagnostic tests; services to manage developing and existing problems; and education, counseling, and referral to reduce high risk behaviors like substance use and poor nutrition.

- The US Preventive Services Task Force (USPSTF) recommends a number of medical interventions related to pregnancy that can best be provided if the woman has comprehensive maternity coverage. Among the USPSTF recommendations are folic acid supplementation, screening for preeclampsia and gestational diabetes, and counseling on the value of breastfeeding.

- Possible barriers to prenatal care include:
  - Lack of insurance
  - Problems with transportation, child care, and the service hours of health care providers
  - Maternal age, income, education, and social/cultural factors

- Prenatal care should begin early and continue regularly.
  - Adequacy of prenatal care varies by race and ethnicity. Native American, non-Hispanic black and Hispanic women are least likely to receive adequate prenatal care.

- Group prenatal care is emerging as a favorable option for many mothers. In group care, a facilitator meets regularly with a group of 8-12 women to discuss their pregnancies and answer questions. Some studies have shown that women who participate in certain group care models are significantly less likely to give birth to a preterm baby (9.8% vs. 13.8% of mothers in individual care). Additionally, among participants with preterm births, their babies have longer gestational ages and higher birth weights than babies born to mothers in individual care.

Source: Group Prenatal Care Information from Thielen, 2012.
In 2003, some states began using the revised birth certificate, which included substantive changes in the collection of prenatal care data. States have been phasing in the revised birth certificate, and as of 2014, 47 states, the District of Columbia, and Puerto Rico had revised prenatal care data. By 2015, all states and the District of Columbia will be using the 2003 revised birth certificate, but this data will not be available until the following year. Until full data is available, the most recent data includes revised birth certificates from 47 states and the District of Columbia.

- In 2014, the rate of early prenatal care in 47 states and the District of Columbia using revised certificates (96% of all births) was 76.7%. 6.0% of women had late or no prenatal care.

- In 2014, as in previous years, non-Hispanic black, Hispanic and non-Hispanic Native American women had higher rates of receiving late or no prenatal care than non-Hispanic white or non-Hispanic Asian women.

- Adolescents have higher rates of receiving late or no prenatal care. Rates for late or no prenatal care decline with age, with women over 30 having much lower rates of late or no prenatal care.

Benefits of Folic Acid

Sufficient folic acid intake before and during pregnancy can reduce the risk of birth defects of the brain and spinal cord known as neural tube defects.

- Each year, about 2,700 pregnancies are affected with neural tube defects. Several studies, including observational and randomized controlled trials, have demonstrated that 50%-70% of these cases could be prevented if women consumed the proper amounts of folic acid before becoming pregnant and during early pregnancy.

- The US Preventive Service Task Force (USPSTF) and the March of Dimes have recommended that, to reduce the risk of having a child with a neural tube defect, women who might become pregnant should consume 400-800 micrograms of synthetic folic acid every day from a vitamin or from fortified foods, in addition to eating a healthy diet rich in natural sources of folate.

- After mandated fortification of enriched grain products with folic acid in 1998, the rate of neural tube defects decreased by 28%.

- While public awareness is improving, most women of childbearing age do not know about the benefits of folic acid. Although 84% have heard of folic acid, only 39% take a daily vitamin containing it. Only 20% know that folic acid prevents birth defects, and only 11% know it should be taken before pregnancy.

- Health professionals have not been the main source of women’s information about folic acid. Among women aware of folic acid, 49% learned about it from the media, but only 33% from their physician or other health care provider.

- Women report various reasons when asked why they did not take a folic acid supplement to prevent neural tube defects: 33% claimed that they forgot, 18% said they did not need to, 14% did not believe it would make a difference and 12% claimed they consumed enough folate from their balanced diet.

Awareness of Folic Acid Benefits among Women of Childbearing Age, 1995 and 2008

- **Heard of folic acid**: 1995 - 52%, 2008 - 84%
- **Knew folic acid should be taken before pregnancy**: 1995 - 2%, 2008 - 11%
- **Knew folic acid can prevent birth defects**: 1995 - 4%, 2008 - 20%
- **Take vitamin containing folic acid daily**: 1995 - 28%, 2008 - 39%

Note: Includes women ages 18-45 only.
Source: Gallup Poll for March of Dimes.

**ONE HEALTHY PEOPLE 2020 OBJECTIVE IS TO INCREASE THE PROPORTION OF WOMEN OF CHILDBEARING POTENTIAL WHO CONSUME AT LEAST 400 MICROGRAMS OF FOLIC ACID TO 26.2%, A 10% INCREASE FROM THE BASELINE RATE OF 23.8% (2003-2006).**

**ANOTHER HEALTHY PEOPLE 2020 OBJECTIVE IS TO REDUCE THE OCCURRENCE OF SPINA BIFIDA BY 10% TO 30.8 CASES PER 100,000 LIVE BIRTHS FROM 34.2 CASES PER 100,000 LIVE BIRTHS (2005-2006).**
Maternal and Childhood Immunization

Prevention of disease through vaccination has been called one of the 10 greatest public health achievements of the 20th century by the Centers for Disease Control and Prevention.

- Rubella (German measles), a major cause of serious birth defects such as deafness and blindness, was declared no longer endemic in the United States in 2005, due to successful vaccination. However, the disease is still introduced to the United States from bordering countries and international travelers, which necessitates ongoing use of the rubella vaccine.

- Flu shots protect pregnant women and their babies. Seasonal flu can cause severe illness in pregnant women, more so than among women who are not pregnant. Pregnant women with the flu also have a greater chance for poor birth outcomes, including premature labor and delivery.

- Pertussis (whooping cough) is highly contagious and potentially fatal to infants. Unvaccinated individuals can contract and spread this serious disease to infants and young children, even if they are not symptomatic. In 2014, 28,660 cases of pertussis were reported in the U.S., but many more go undiagnosed and unreported.

- Vaccines are cost effective. For example, for every dollar spent, measles/mumps/rubella vaccine saves $26; diphtheria/tetanus/acellular pertussis vaccine saves $27; perinatal hepatitis B vaccine saves nearly $15; and varicella (chicken pox) vaccine saves more than $5.

- Immunization levels have dropped in certain populations in recent decades, and some otherwise preventable infectious diseases have made dramatic reappearances. A portion of this trend can be traced back to nonmedical vaccine exemptions. Children who are not vaccinated can place not only themselves, but a whole community at risk. Nationally, the CDC reports the rate of nonmedical exemptions for children entering kindergarten is 1.7%. However, in some communities the rate of personal exemptions among children entering kindergarten can exceed 20%. Some states have begun to change their laws regarding exemptions, given the potential negative impact of low vaccination rates on public health.

- The Advisory Committee on Immunization Practices (ACIP) recommends that infants be immunized against 14 diseases before age two. However, 19% of toddlers are vulnerable to serious illnesses (including polio, measles, mumps, rubella, diphtheria, tetanus, whooping cough, hepatitis B, and varicella) because they have not received all the ACIP-recommended vaccines on time.

Women who smoke during pregnancy are more likely than non-smokers to have a low birthweight or preterm baby. Babies of smokers weigh, on average, 200 grams less than nonsmokers’ babies.

- Pregnant women are less likely to smoke than other women. In 2011-2012, 15.9% of pregnant women age 15 to 44 reported smoking cigarettes during the past month compared to 24.6% of non-pregnant women.

- Among the 46 states and DC using the revised birth certificate who report smoking rates, the proportion of pregnant women who report smoking varies substantially by race/ethnicity: 18.5% of non-Hispanic Native American, 12.2% of non-Hispanic white, 7.1% of non-Hispanic black, 2.0% of Hispanic women, and 1.0% of non-Hispanic Asian women reported smoking during pregnancy.

- Studies show that women who stop smoking before becoming pregnant or early in pregnancy decrease their risk of having a low birthweight baby to nearly that of women who have never smoked.

- Smoking cessation services for pregnant women are among a handful of interventions that save enough in later medical expenses to completely offset the initial investment and result in cost savings. It has been estimated that $122 million in annual NICU costs could be attributed to smoking.

- Pregnant women on Medicaid are more likely than other pregnant women to smoke, according to state data. As of October 1, 2010, the Affordable Care Act required all Medicaid programs to cover comprehensive smoking cessation services, including both counseling and pharmacotherapy, without cost-sharing for pregnant women (Section 4107).

Alcohol and Other Drug Use

Use of alcohol and other drugs during pregnancy is related to higher rates of a wide range of adverse birth outcomes, including prematurity, low birthweight, and birth defects.

- Among pregnant women ages 18-44, 10.2% reported alcohol use and 3.1% reported binge drinking (4 or more drinks on at least one occasion during the past month) during 2011-2013.

- Heavy alcohol consumption during pregnancy can lead to fetal alcohol syndrome (FAS), which affects roughly one in 1,000 newborns annually. Alcohol abuse is the leading known preventable cause of intellectual disability.

- From 2011-2013, 18.2% of women of child bearing age (18-44) reported binge alcohol use.

- Among pregnant women, 5.4% reported using illicit drugs during 2012-2013. Alcohol consumption, cigarette smoking, and illicit drug use are linked.

- Drug use among pregnant women can lead to neonatal abstinence syndrome (NAS), in which newborns experience drug withdrawal shortly after birth due to drug exposure in utero. Today, one of the most common causes of NAS is maternal use or abuse of opioids during pregnancy.

- Between 2000 and 2009, the number of mothers found to be using opioids during pregnancy increased from 1.19 to 5.63 per 1,000 US hospital births. From 2000-2012, NAS diagnoses increased from 1.20 to 5.80 per 1000 hospital births per year.

Binge Drinking among Women Ages 18-44 during Past Month, 2006-2014


Rates of NAS per 1000 Hospital Births per year, United States 2000-2012

Obesity

Being obese (defined as having a Body Mass Index of 30 or more) or overweight (having a Body Mass Index of 25 or greater) increases the risk of infertility and poor pregnancy outcomes.

- Women who are overweight or obese are at risk for serious pregnancy-related medical complications such as hypertension and diabetes that contribute to prematurity and increase the likelihood of cesarean section.

- Babies born to mothers who are obese are more likely to have health problems, including increased risk of neural tube defects, higher rates of birth injuries, low Apgar scores, more admissions to neonatal intensive care units, and higher rates of prenatal death.

- The proportion of women of childbearing age (age 18-44) who were obese increased from 20.2% in 2004 to 27.2% in 2014, an increase of 35%.

- Healthy lifestyle changes before, during and after pregnancy can help to avoid some of these complications associated with obesity.

Note: The Apgar score is designed to check an infant’s condition at one minute and five minutes after birth. Infants with low Apgar scores may need additional monitoring or special care.

Obesity among Women Ages 18-44, 2004-2014

The prevalence of being obese or overweight is a major health concern in the United States, and was named one of the ten leading health indicators used to measure the health of the nation in Healthy People 2020.

Note: Obesity is defined as a Body Mass Index of 30 or more.

Home Visiting Programs

Home visiting programs are designed to work with expectant parents to improve developmental, educational and health outcomes for young children and their families. Home visiting programs work with families to ensure they receive adequate prenatal care and to promote healthy behavior such as quitting smoking and maintaining a healthy diet.

- Benefits of home visiting include increased school readiness and lower health costs.

- Evaluations of home visiting programs have shown improvements in birth outcomes, child development and maternal and child health, as well as decreased rates of child maltreatment and juvenile justice issues.

- Home visiting programs can save money. A cost benefit analysis of the Nurse-Family Partnership program found that, on average, every dollar spent saved $2.88 due to reduced mental health and criminal justice costs, and increased economic sufficiency and employment. The same study showed that up to $5.70 can be saved for the highest risk populations. The benefit to society is approximately $26,000 per family served on average, and $41,000 among high-risk families.

- The Affordable Care Act authorized an initial investment of $1.5 billion from 2010-2014 for home visiting with demonstrated effectiveness. MIECHV funds grants for home visiting with demonstrated effectiveness. Currently, 17 program models have been deemed effective. In 2015, Congress extended funding for the MIECHV program as part of the Medicare Access and CHIP Reauthorization Act of 2015. This act provided $400 million per year for 2016 and 2017.

Source: Benefits from Roman et al 2014 and Karoly et al, 2005. Department of Health and Human Services, Home Visiting Evidence of Effectiveness. MIECHV grant information from HRSA.
Health insurance coverage affects how people use health care services. In general, individuals without health insurance report poorer health status than those with health insurance. They are also less likely to have a usual source of medical care and more likely to delay or forgo needed health care services.

- Uninsured women receive fewer prenatal services and report greater difficulty in obtaining needed care than women with insurance, an Institute of Medicine study concluded. In 2009, 23% of pregnant women reported being uninsured in the month before pregnancy; however, only one percent (1%) reported being uninsured at delivery.

- Health insurance status is the single most important factor in determining whether health care is accessible to children when they need it, according to another Institute of Medicine study.

- In 2013-2014, over one-quarter of uninsured children had no usual source of medical care (28.1%) compared with only 1.8% of privately insured children and 3.1% of children with public insurance.

- From 2009-2011, 86.8% of all women reported having a usual source of care.
  - Non-Hispanic white women reported having a usual source of care most often (89.3%), compared to 85.3% of non-Hispanic black women, 85.1% of Native American women and 85.7% of Asian women. Hispanic women have the lowest rates of having a usual source of care (78.6%).
  - Among women without health insurance, only 56.2% had a usual source of care.

Children without a Usual Source of Medical Care, by Type of Insurance Coverage, 2014

<table>
<thead>
<tr>
<th>Percent</th>
<th>Private</th>
<th>Medicaid/Other Public</th>
<th>Uninsured</th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td>1.8</td>
<td>3.1</td>
<td>28.1</td>
</tr>
</tbody>
</table>


Women without a Usual Source of Medical Care, by Type of Insurance Coverage, 2009-2011

<table>
<thead>
<tr>
<th>Percent</th>
<th>Private</th>
<th>Public</th>
<th>Uninsured</th>
</tr>
</thead>
<tbody>
<tr>
<td>45</td>
<td>6.5</td>
<td>8.2</td>
<td>43.8</td>
</tr>
</tbody>
</table>

Health Insurance Coverage for Women of Childbearing Age

Health insurance is important for assuring access to care for women of childbearing age.

- One in six women of childbearing age (15 to 44) – 10.2 million – was uninsured in 2014. These women accounted for 27% of all uninsured Americans; 65% had family incomes below 200% percent of the federal poverty level.

- In 2014, Hispanic women had the highest rate of uninsurance (29.9%) – which was more than double that of non-Hispanic white women (11.2%). Non-Hispanic Native American, non-Hispanic black women and non-Hispanic Asian women also have higher rates of uninsurance compared to non-Hispanic white women (21.9%, 17.1% and 11.5%, respectively).

- Lack of health insurance remains a problem for some pregnant women, although they are less likely to be uninsured than other women. In 2013, 4.4% of women who delivered their babies in hospitals were uninsured.

- Prior to implementation of the Affordable Care Act, individual health insurance plans frequently excluded maternity coverage entirely or only made it available subject to additional premiums or limitations. In 2011, only 62% of private (non-employer sponsored) coverage provided maternity coverage for enrollees. As of 2014, non-grandfathered private health plans must cover maternity and newborn care as an “essential health benefit” under the Affordable Care Act.

- In 2016 open enrollment, 12.7 million individuals were enrolled in coverage through the Marketplaces established under the Affordable Care Act.

Women Ages 15–44, by Type of Health Insurance Coverage, 2014

![Chart showing the percentage of women ages 15–44 by type of health insurance coverage in 2014.]

Source: U.S. Census Bureau, 2014

Women Ages 15–44 Who Are Uninsured, by Race/Ethnicity, 2014

![Chart showing the percentage of uninsured women ages 15–44 by race/ethnicity in 2014.]


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a People of Hispanic origin may be of any race. Racial groups include only non-Hispanic.

b Native American includes American Indian and Alaska Native.
Health insurance coverage is a major predictor of access to health care for children. The majority of children are covered by private insurance (53.0%), a large proportion are enrolled in public insurance either through Medicaid or the Children’s Health Insurance Program (41.4%) and just over six percent (6.3%) of children are uninsured.

- In 2014, over 7 million children lacked health insurance, representing 6.2% of the nation’s 78.2 million children under age 19.

- In 2012, the majority of children without insurance (64.1%) lived in households with an income below 200% of the federal poverty level. Among uninsured children, 3.2 million were eligible for Medicaid or CHIP but not enrolled.

- Native American children had the highest rates of uninsurance, over twice that of non-Hispanic white children – 11.5%, compared with 4.8%. Higher rates of uninsurance compared to non-Hispanic white children were also found among Hispanic (10.3%) and non-Hispanic black (5.1%) children whereas Asian (4.8%), and Native Hawaiian/Pacific Islander children (4.7%) have similar rates to white children.

- Newborn birth was the most common reason for uninsured hospitalizations, accounting for nearly 150,000 uninsured stays in 2012 (7.2% of all uninsured stays).

Children Under Age 19, by Type of Health Insurance Coverage, 2014

<table>
<thead>
<tr>
<th>Type of Coverage</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employer Based</td>
<td>51.1</td>
</tr>
<tr>
<td>Other Private</td>
<td>7.2</td>
</tr>
<tr>
<td>Medicaid</td>
<td>37.8</td>
</tr>
<tr>
<td>Other Public</td>
<td>3.3</td>
</tr>
<tr>
<td>Uninsured</td>
<td>6.3</td>
</tr>
</tbody>
</table>


Children Under Age 19 Who Are Uninsured, by Race/Ethnicity, 2014

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>4.8</td>
</tr>
<tr>
<td>Black</td>
<td>5.1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>10.3</td>
</tr>
<tr>
<td>Native American</td>
<td>11.5</td>
</tr>
<tr>
<td>Asian</td>
<td>4.8</td>
</tr>
<tr>
<td>Native Hawaiian/Pacific Islander</td>
<td>4.7</td>
</tr>
<tr>
<td>All Races/Ethnicities</td>
<td>6.3</td>
</tr>
</tbody>
</table>

Medicaid is the major public source of funding for health care services provided to pregnant women, infants, and children.

- A joint federal-state health insurance program for low-income Americans, Medicaid financed 45% percent of hospital births in 2010 and covered about 31 million children in 2014.

- Medicaid is a key source of health insurance coverage for preterm infants and those born with birth defects.
  - Over half (53.9%) of hospital stays for preterm and low birthweight infants were financed by Medicaid in 2013. Hospital costs for these babies averaged $66,313.
  - Over one-third (34.7%) of infant hospital stays due to birth defects were covered by Medicaid in 2013.

- The Affordable Care Act directed states to expand Medicaid coverage to all eligible individuals up 138% of the federal poverty level. However, the Supreme Court ruled that states could decide individually whether or not to expand their Medicaid programs. As of the end of 2015, 30 states and Washington, DC have expanded their Medicaid programs, while the rest have not.

- The Affordable Care Act has increased insurance coverage among women of childbearing age in all states. Overall, the uninsurance rate among women of childbearing age decreased from 19.6% to 13.3% between summer/fall 2013 and winter 2014/2015. Gains in coverage for low-income women were greater for women in states that expanded Medicaid.

- For low-income women in 29 states, the Medicaid\textsuperscript{a} family planning waiver allows states to provide access to family planning services for women who would not otherwise qualify for Medicaid. These services can be critical for improving maternal and child health, especially in states that have not expanded Medicaid under the Affordable Care Act. This federal family planning benefit covers a number of services that fall under preconception care (e.g., sexually transmitted infection testing/treatment).

\textsuperscript{a} Family planning waiver programs vary by state. States have the option to provide family planning services to women under a defined income threshold, to women who have exhausted Medicaid postpartum coverage, and/or to women who have lost Medicaid for any reason.

Medicaid Enrollment and Expenditures, by Enrollee Characteristics, 2014

Enrollees
Total=68 Million

- Children 48%
- Adults 27%
- Elderly 9%
- Disabled 15%

Expenditures
Total=$397.6 Billion

- Children 21%
- Adults 15%
- Elderly 21%
- Disabled 42%

Source: Kaiser Commission on Medicaid and the Uninsured, 2015.

Family Planning Waiver Programs, by State, 2014

Sources: Guttmacher Institute, 2015.

No Waiver (22)
Income-Based (26)
Postpartum (2)
Loss of Medicaid (1)
In 2014, 5.5 million children were enrolled in the Children’s Health Insurance Program (CHIP). This joint federal-state program was re-authorized in 2015 to secure funding to cover those currently enrolled, as well as an additional four million uninsured children.

- In 2009, the Children’s Health Insurance Program Reauthorization Act (CHIPRA) authorized federal matching funds for new state options to expand coverage. These provisions were then reauthorized through 2017 as part of the Medicare and CHIP Reauthorization Act of 2015 (MACRA). State options include:
  - Enroll income-eligible pregnant women;
  - Enroll legal immigrant pregnant women and children; and
  - Combine CHIP with private insurance.

- As of January 2015, seven states plus the District of Columbia were using CHIP funds to expand Medicaid coverage, 17 states were covering children through a separate program, and 27 were using a combination of these two approaches.

- States that elect to use CHIP funds to operate a separate state-designed program may choose a benefit package that differs from Medicaid’s benefits. These programs may also require enrollees to pay premiums, copayments, or both, although cost sharing is subject to limitations. As of January 2015, 30 states required premiums and 26 states required copayments.

- CHIP income eligibility varies among the states and ranges from 150 to 400% of the federal poverty level. Nearly all states cover children with family incomes up to or over 200 percent of the federal poverty level ($40,180 for a family of three in 2015).

- As of January 2015, 19 states have exercised one or both of the options available to them to extend CHIP coverage to pregnant women.

Children’s Health Insurance Program Enrollment, 2006-2014

In Millions

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
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<tbody>
<tr>
<td></td>
<td>6.6</td>
<td>7.1</td>
<td>7.4</td>
<td>7.7</td>
<td>7.7</td>
<td>8.2</td>
<td>8.4</td>
<td>8.1</td>
<td>8.1</td>
</tr>
</tbody>
</table>

Note: Number of children ever enrolled during the fiscal year.

CHIP Programs that Cover Pregnant Women, 2015

2014 Income eligibility levels for pregnant women
(% Federal Poverty Level)

<table>
<thead>
<tr>
<th>State</th>
<th>Medicaid</th>
<th>CHIP</th>
<th>Coverage Authority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arkansas</td>
<td>0-209</td>
<td>0-210</td>
<td>UCO&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>California</td>
<td>0-208</td>
<td>0-322</td>
<td>UCO</td>
</tr>
<tr>
<td>Colorado</td>
<td>0-195</td>
<td>196-260</td>
<td>SPA&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>DC</td>
<td>0-206</td>
<td>206-324&lt;sup&gt;*&lt;/sup&gt;</td>
<td>SPA, ICHIA&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
<tr>
<td>Illinois</td>
<td>0-208</td>
<td>0-209</td>
<td>UCO</td>
</tr>
<tr>
<td>Louisiana</td>
<td>0-133</td>
<td>0-200</td>
<td>UCO</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>0-200</td>
<td>0-200</td>
<td>UCO</td>
</tr>
<tr>
<td>Michigan</td>
<td>0-195</td>
<td>0-195</td>
<td>UCO</td>
</tr>
<tr>
<td>Minnesota</td>
<td>0-278</td>
<td>0-278</td>
<td>UCO</td>
</tr>
<tr>
<td>Nebraska</td>
<td>0-194</td>
<td>0-197</td>
<td>UCO</td>
</tr>
<tr>
<td>New Jersey</td>
<td>0-194</td>
<td>194-200</td>
<td>SPA, ICHIA</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>0-133</td>
<td>0-185</td>
<td>UCO</td>
</tr>
<tr>
<td>Oregon</td>
<td>0-185</td>
<td>0-185</td>
<td>UCO</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>0-190</td>
<td>0-253</td>
<td>Waiver&lt;sup&gt;4&lt;/sup&gt;, SPA, UCO</td>
</tr>
<tr>
<td>Tennessee</td>
<td>0-195</td>
<td>0-250</td>
<td>UCO</td>
</tr>
<tr>
<td>Texas</td>
<td>0-198</td>
<td>0-202</td>
<td>UCO</td>
</tr>
<tr>
<td>Virginia</td>
<td>0-143</td>
<td>143-205</td>
<td>Waiver</td>
</tr>
<tr>
<td>Washington</td>
<td>0-193</td>
<td>0-193</td>
<td>UCO</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>0-301</td>
<td>0-301</td>
<td>UCO</td>
</tr>
</tbody>
</table>

<sup>1</sup> State plan option to cover unborn child from conception to birth.
<sup>2</sup> State plan option to cover targeted low-income pregnant women through a state plan amendment (SPA).
<sup>3</sup> State plan option to cover lawfully residing immigrant pregnant women according to Immigrant Children’s Health Improvement Act (ICHIA).
<sup>4</sup> Section 1115 waiver to cover uninsured pregnant women.

Source: March of Dimes Office of Government Affairs, based on analysis conducted by National Academy for State Health Policy.
States can streamline eligibility determinations for Medicaid and CHIP to reduce delays in enrollment of eligible pregnant women and children, thus enabling prompt access to health care. Both CHIPRA and the Affordable Care Act provided funding to streamline enrollment and retention.

- **Presumptive eligibility** allows states to cover applicants temporarily until eligibility can be fully determined. States may permit health care providers, schools, and other agencies to determine presumptive eligibility. Medicaid programs in 27 states and the District of Columbia provided presumptive eligibility to pregnant women in 2015, while 15 states and the District of Columbia provided presumptive eligibility for children in Medicaid and nine did so in CHIP.

  - Presumptive eligibility increases the proportion of pregnant women on Medicaid who receive early prenatal care.
  
  - Parents of uninsured children reported being more likely to enroll their children in Medicaid if they could do so immediately or through their doctor’s office or clinic.

- **Continuous eligibility** allows states to provide coverage to children for up to 12 months, regardless of changes in family income or eligibility. All states must extend Medicaid coverage to pregnant women through 60 days after delivery and automatically enroll infants born to women covered by Medicaid. In 2015, 23 states provided 12 months of continuous eligibility for children with Medicaid. Twenty-six CHIP programs have also adopted the 12 month continuous coverage policy.

  - Continuous eligibility can prevent needless coverage disruptions and can promote more reliable access to prevention and primary health care services, which can in turn lead to better health outcomes for children.
  
  - Renewal processes such as telephone follow-up to mail notices, reduced verification requirements, and use of eligibility information from other state programs can help prevent eligible children from losing coverage.

The Affordable Care Act and Women and Children

The Patient Protection and Affordable Care Act of 2010 (ACA) included a variety of provisions which aim to expand access to care. Many of these provisions benefit women of childbearing age and children:

- As of August 2011, most private health plans must cover preventive care without cost sharing, including prenatal care, regular well-child visits, well-woman visits, screening for gestational diabetes, domestic violence screening, breastfeeding supplies, and contraceptive services.

- As of 2014, women who buy insurance in the Marketplace have access to more comprehensive coverage.
  - Health plans must cover maternity and newborn care as one of the ten categories of “essential health benefits.”
  - Health plans may not base premiums on gender or health status.
  - Health plans may not deny coverage based on pre-existing conditions, such as pregnancy.
  - If families meet certain income criteria, the government offers tax credits to help pay for insurance.

- Young adults age 19-25 may be covered under their parents’ employer-sponsored insurance. Since 2011, over 5.5 million young adults have gained coverage through their parents’ insurance. Nearly half (45%) of women age 18-25 reported receiving health insurance through a parent’s plan in 2013.

Amino Acid Metabolism Disorders

Phenylketonuria (PKU) (>1 in 25,000).
Inability to process the essential amino acid phenylalanine, which accumulates and damages the brain. Can lead to severe mental retardation unless detected soon after birth and treated with a special formula and a low-protein diet, continued indefinitely.

Maple syrup urine disease (<1 in 100,000).
Genetic metabolic disorder with mild to severe symptoms, which can lead to mental retardation or death. Treatment consists of a special diet, continued indefinitely.

Homocystinuria (<1 in 100,000). Lack of an enzyme that converts the amino acid homocysteine into cystathionine, needed for normal brain development. Untreated, leads to mental retardation, eye problems, skeletal abnormalities, and stroke. Treatment consists of a special diet, one or more vitamins (B6 or B12), and other supplements (betaine).

Citrullinemia (<1 in 100,000). Buildup of citrulline and ultimately ammonia, which untreated can lead to seizures, coma, brain damage, and death. Treatment with low-protein diet, medications to prevent ammonia buildup, and nutritional supplements allows normal development.

Argininosuccinic acidemia (<1 in 100,000). Buildup of argininosuccinic acid and ultimately ammonia, leading to brain swelling, coma, and sometimes death. Treatment consists of a low-protein diet, frequent meals, medications to prevent ammonia buildup, and nutritional supplements, and sometimes liver transplant.

Tyrosinemia type 1 (<1 in 100,000). Lack of an enzyme that causes the byproducts of the amino acid tyrosine, particularly a very toxic compound (succinylacetone), to build up in the liver. Fatal liver and kidney failure may result. Drug therapy is effective.

Organic Acid Metabolism Disorders

Isovaleric acidemia (<1 in 100,000). Inability to process the amino acid leucine. Can cause coma, brain damage, or death in infancy, or emerge later in childhood after infectious illness. Early diagnosis and treatment with low-protein diet and nutritional supplements allow most children to develop normally.

Glutaric acidemia type I (>1 in 75,000).
Inadequate levels of an enzyme that helps break down the amino acids lysine, hydroxylysine, and tryptophan, which are building blocks of protein. Often unrecognized for up to 18 months, until childhood illness triggers onset of symptoms. Without early diagnosis and prompt treatment when needed, can lead to brain damage, low muscle tone, cerebral palsy-like symptoms, and death.

Hydroxymethylglutaric aciduria (<1 in 100,000). Inability to process leucine, leading to low blood sugar and accumulation of several organic acids, especially after illness or missed meals. Untreated, can lead to brain damage, mental retardation, coma, and death. Treatment includes a diet low in protein and fat, and high in carbohydrates.

Multiple carboxylase deficiency (<1 in 100,000). Defect in an enzyme that activates several other enzymes, leading to buildup of lactic acid and other organic acids. Untreated, can cause brain damage, coma, and death. Symptoms, including skin rashes and hair loss, usually begin between birth and 15 months. Treatment with a B vitamin, biotin, allows normal development.

Methylmalonic acidemia due to mutase deficiency (>1 in 75,000). Defect in processing four amino acids, resulting in illness in first week of life. Severity varies, but death during first month and lifelong brain damage are common. Treatment includes low-protein diet, vitamin B12 injections, and nutritional supplements.

Methylmalonic acidemia, cblA and cblB forms (<1 in 100,000). Inherited vitamin metabolism defect. Can lead to buildup of acids in blood, brain damage, seizures, paralysis, coma, and death. Treatment includes B12 injections and a low-protein diet.

3-Methylcrotonyl-CoA carboxylase deficiency (>1 in 75,000). Defect in processing leucine, leading to brain damage, seizures, liver failure, and infant death, or sometimes no symptoms until adulthood. Symptoms may develop after childhood illness. Treatment includes a low-protein diet.

Propionic acidemia (>1 in 75,000). Defect in processing four amino acids leading to illness in newborns, including brain damage, coma, and death. Even with treatment, which includes a low-protein diet and nutritional supplements, some children have development delays, seizures, increased muscle tone, frequent infections, and heart problems.

Beta-ketothiolase deficiency (<1 in 100,000). Periodic episodes of acid buildup, often triggered by illness, which can lead to coma, brain damage, and death. Intravenous treatment to regulate blood sugar and blood acid levels can permit normal development.
Fatty Acid Oxidation Disorders

Medium-chain acyl-CoA dehydrogenase deficiency (>1 in 25,000). Seemingly well infants and children suddenly develop seizures (due to low blood sugar), liver failure, coma, and death. Treatment includes nutritional supplements and frequent meals.

Very long-chain acyl-CoA dehydrogenase deficiency (>1 in 75,000). Unless treated, infants often develop heart and liver failure, dying before age one. Treatment includes a high-carbohydrate/low-fat diet, nutritional supplements, frequent meals, and limiting exercise.

Long-chain 3-OH acyl-CoA dehydrogenase deficiency (>1 in 75,000). Symptoms can begin soon after birth, resulting in heart, lung or liver failure, and death. Treatment includes a high-carbohydrate/low-fat diet, nutritional supplements, and frequent meals.

Trifunctional protein deficiency (<1 in 100,000). Seemingly healthy infants can die of what appears to be sudden infant death syndrome. Other infants may develop low muscle tone, seizures, heart failure, and coma, often following illness. Treatment based on frequent meals, a low-fat diet, and nutritional supplements.

Carnitine uptake defect (<1 in 100,000). Cells cannot readily absorb carnitine, needed to transfer fatty acids into mitochondria (which supply cells with energy). Results include low blood sugar and sudden death in infancy. Older children may present with progressive heart failure. High-dose carnitine permits normal development.

Hemoglobinopathies

Sickle cell anemia (Hb SS) (>1 in 5,000; in African-Americans, 1 in 400). Blood disease that can cause pain, vital organ damage, stroke, and sometimes childhood death. Young children are especially prone to dangerous bacterial infections like pneumonia and meningitis. Vigilant medical care and penicillin can reduce the risk of these effects.

Hb S/Beta–Thalassemia (Hb S/Th) (>1 in 50,000). A form of sickle cell anemia, in which the child inherits one sickle cell gene and one gene for beta thalassemia, another inherited anemia. Symptoms are milder than for Hb SS, though severity varies. Routine treatment with penicillin may not be recommended for all affected children.

Hb S/C disease (Hb S/C) (>1 in 25,000). Another form of sickle cell disease, in which the child inherits one sickle cell gene and one gene for another abnormal type of hemoglobin. Hb S/C tends to be milder than Hb SS; therefore, treatment with penicillin may not be recommended.

Lysosomal Storage Disorders

Mucopolysaccharidosis type I (MPS I). (1 in 100,000) Lysosomes cannot break down complex sugars which causes undigested sugar molecules and other harmful substances to build up in cells throughout the body, resulting in a variety of symptoms. MPS I comprises a wide spectrum of severity and symptoms. Detecting MPS I early and beginning treatment may prevent or delay some of the severe health outcomes associated with the condition.

Pompe disease (1 in 40,000). Pompe is caused by a defect in acid alpha-glucosidase (GAA), resulting in glycogen accumulation primarily in cardiac and skeletal muscle resulting in a variety of symptoms. There are three forms of Pompe which differ in regards to disease severity and age of onset. The symptoms and long term outcome of each form vary widely. Pompe disease is an autosomal recessive disorder. For the best possible outcome, it is important to detect Pompe early and begin proper treatment immediately.

X-linked Adrenoleukodystrophy (X-ALD). (1 in 17,000). Certain fats (very long chain fatty acids, or VLCFAs) cannot be broken down in the body. These fats build up and affect the nervous system and the adrenal glands. The buildup of VLCFAs may disrupt the myelin of the nerve cells in the brain and spinal cord causing the myelin to breakdown, which reduces the ability of the nerves to transmit information to the brain. Without myelin, the nervous system cannot function properly causing symptoms such as difficulties swallowing or weakness in the legs. Symptoms vary depending on the type and age of onset and other factors which are not well understood.
Other Inherited and Non-Genetic Disorders

**Congenital hypothyroidism** (>1 in 5,000). Thyroid hormone deficiency that severely retards growth and brain development. If detected shortly after birth, can be treated with oral doses of thyroid hormone to permit normal development.

**Biotinidase deficiency** (>1 in 75,000). An inherited disorder resulting in lack of the enzyme that recycles the vitamin biotin. May cause frequent infections, uncoordinated movement, hearing loss, seizures, and mental retardation. Undiagnosed and untreated, can lead to coma and death. If condition is detected soon after birth, problems can be prevented with oral high-dose biotin.

**Congenital adrenal hyperplasia (CAH)** (>1 in 25,000). A group of inherited disorders resulting from deficiencies of hormones produced by the adrenal gland. Severe forms of CAH, if undetected and untreated, cause life-threatening salt loss via urine. Treatment includes hormone replacement.

**Galactosemia** (>1 in 50,000). Lack of the liver enzyme needed to convert galactose, a major sugar in milk, into glucose (blood sugar). Galactose then accumulates in and damages vital organs, leading to blindness, severe mental retardation, infection, and death. Milk and other dairy products must be eliminated from the baby’s diet for life. This greatly improves the outlook for affected infants, but risk of mild developmental delays remains.

**Hearing impairment** (>1 in 5,000). Among the most common abnormalities present at birth. Without early testing, most babies with hearing loss are not diagnosed until age two or three. By then, they often have delayed speech and language development. Early diagnosis allows use of hearing aids by six months, helping prevent serious speech and language problems.

**Cystic fibrosis** (>1 in 5,000). A common inherited disorder, resulting in lung and digestive problems, and death by age 35, on average. Early diagnosis and treatment may improve the growth of babies and children with CF.

**Critical Congenital Heart Defects (CCHD)** (18 in 10,000). A group of seven heart defects consisting of hypoplastic left heart syndrome, pulmonary atresia (with intact septum), teratology of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia and truncus arteriosus. Babies born with a CCHD are at significant risk of disability or death if not diagnosed soon after birth.

**Severe combined immunodeficiency (SCID)** (>1 in 100,000). A group of rare inherited disorders characterized by defects in two critical immune system cells that are normally mobilized by the body to combat infections. SCID has also been referred to in the popular media as the “bubble boy disease.” Without treatment, infants with SCID are more susceptible to and can develop recurrent infections, leading to failure to thrive and oftentimes death.

*The symbols < and > denote “less than” and “greater than”, respectively. Terms are ordered in accordance with the table on page 23, which summarizes state requirements.*
State Data and Online Access

State level data for many of the indicators included in this book may be found online, including:

- Infant Mortality Rates
- Preterm Birth Rates
- Low Birthweight Rates
- Health Insurance Rates for Women and Children
- Income Eligibility for Medicaid and CHIP
- Medicaid Enrollment and Expenditures
- CHIP Enrollment and Expenditures
- Federal Matching Rates for Medicaid and CHIP
- Births funded by Medicaid


Centers for Disease Control and Prevention, National Center for Immunization and Respiratory Diseases, 2011. *Pregnant Women Need a Flu Shot.*


Kaiser Family Foundation. 2014. Women and Health Care in the Early Years of the ACA: Key Findings from the 2013 Kaiser Women’s Health Survey.


Kaiser Family Foundation. 2015. New Estimates of Eligibility for ACA Coverage among the Uninsured.


Patient Protection and Affordable Care Act (Affordable Care Act), P.L. 111-148, Section 4107, 2010.


Sommers B.D. and others. 2013. “The Affordable Care Act has led to significant gains in health insurance and access to care for young adults.” *Health Affairs.* 32(1):165-74


