

*Promoting the Health of Babies, Children
and Adults and Enhancing the Potential
for Full, Productive Living*



Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
Healthy Beginnings. Healthy Lives.
Fiscal Year 2009 • Annual Report



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Paying Tribute

On August 11, 2009, the world lost one of its great champions for people with intellectual disabilities – as Eunice Kennedy Shriver, the founder of Special Olympics, passed away. We remember her for her unwavering dedication to persons with intellectual disabilities. She was a leader

in changing attitudes about how our society views people with disabilities. Her son Timothy Shriver noted, “She believed that people with intellectual disabilities could – individually and collectively – achieve more than anyone thought possible. This much she knew with unbridled faith and certainty.” The memory of her devotion, enthusiasm, and tireless efforts in public service are an inspiration to all.

On her passing, President Barack Obama said she will be remembered above all, “...as a champion for people with intellectual disabilities, and as an extraordinary woman who, as much as anyone, taught our nation – and our world – that no physical or mental barrier can restrain the power of the human spirit.” We at CDC could not agree more. As we mourn her passing, we strengthen our resolve to do our part in carrying forth her vision.

About the Centers for Disease Control and Prevention (CDC).

CDC’s mission is to collaborate to create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury and disability, and preparedness for new health threats.

A Public Health Approach. What does it mean to take “a public health approach”? By definition, public health focuses on preventing disease, promoting health, and prolonging life. It addresses population-level health concerns rather than individual-level health issues. Tracking and surveillance of disease patterns and outbreaks are foundational to public health. Scientific research is the basis for development of health education and outreach programs, as well as policy interventions, that change the lives of people and the communities in which they live, work, and play.

Imagine a day when...

Every child is born with the best health possible. A day when we can define the causes of and prevent complications of blood disorders like hemophilia, sickle cell disease, and clotting disorders that lead to clots that disable or kill. A day when we can explain why some children have a birth defect like congenital heart disease or spina bifida, or have a developmental disability like autism or cerebral palsy, while others do not. Imagine a day when we can prevent all birth defects and developmental disabilities. A day when all children, with and without disabilities, live in environments where their social, emotional, physical, and educational needs are met, and they can reach their full potential.

This is the day that we at CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) are working towards. Our dedicated team of scientists, epidemiologists, and public health experts work passionately to find risk factors, causes, and interventions to improve the lives of all people. Our commitment is driven by stark realities:

- 1 in every 33 babies born in the United States will be affected by a birth defect.
- Approximately 50 million people of all ages in the United States have a disability as a result of an injury or health problem.
- At least 100,000 people a year die from complications of deep vein thrombosis (DVT), blood clots in the legs.

At NCBDDD, our mission is to improve the lives of the people and families impacted by and at risk for these conditions and many more. Working together with partner organizations, families and communities, health care professionals, government health organizations, and health associations, we strive to advance the science related to birth defects, developmental disabilities, disability and health, and blood disorders.

This report shares some of the key ways we have impacted lives over this past year, the investments we are making in research, how we are working with our partners and stakeholders to turn dreams into reality, and what we hope for in the future. Together, we can make advancements by addressing our targeted priorities:

- Assuring child health through prevention, screening, and early identification.
- Improving the health of people with disabilities by addressing risk factors for chronic conditions and infections.
- Preventing deep vein thrombosis and bleeding disorders in women.

As the director of NCBDDD, I pledge to continue this quest for greater knowledge, better programs, and enhanced capacity on behalf of every child and adult impacted by a birth defect, developmental or physical disability, blood disorder, or any obstacle keeping them from optimal growth and development. They deserve to see the promises of tomorrow become today's reality.

Sincerely,



Edwin Trevathan, MD, MPH

Director, National Center on Birth Defects and Developmental Disabilities

Assuring Child Health: Preventing Birth Defects and Developmental Disabilities

With more than 4 million births annually in the United States, chances are you know someone who has recently given birth. Every woman needs accurate and clear health information about how to care for herself – and if she is pregnant or planning to become pregnant, she has additional informational needs to assure the health of her unborn baby. CDC conducts important research to learn more about what women can do even before they become pregnant to prevent birth defects and other developmental problems. For children born with a birth defect or developmental disability, we know that early care and special intervention services will greatly improve their long-term outcomes.

Impacting Lives. Every day, we are working to learn more about how to prevent birth defects and developmental disabilities, develop interventions, and provide important health information. For children who are born with a birth defect or developmental disability, we continue to focus attention on the benefits of early diagnosis and treatment. Below are a few examples of accomplishments in 2009 that impacted infants, women, and families:

- The 2009 H1N1 flu pandemic played out in historic ways. Our studies identified that pregnant women were disproportionately affected by severe 2009 H1N1 influenza. **Pregnant women make up 1% of the U.S. population but account for 6% of the 2009 H1N1 influenza deaths.** Children with certain chronic medical conditions such as asthma and cerebral palsy were also at increased risk for complications and death from 2009 H1N1 virus infection. **About 20% of all H1N1 deaths occurred among children, and two-thirds of these children had at least one underlying chronic medical condition.**
- While much progress has been made in the prevention of neural tube defects since mandatory flour fortification began in 1998, there are still critical gaps for certain high-risk groups. **Research addressing one such gap found that if corn masa flour was fortified, Mexican-American women (ages 15–44) could increase their total usual daily folic acid intake by almost 20%.**

- **Results from our research indicate the latest prevalence of binge drinking among pregnant women was nearly 2% and among non-pregnant women of child-**

bearing age was 12%. This high level of binge drinking among non-pregnant women is concerning because 50% of all pregnancies are unplanned, suggesting that many pregnancies are exposed to harmful levels of alcohol early in pregnancy.

Drinking alcohol during pregnancy can lead to fetal alcohol spectrum disorders (FASD) and can mean lifelong, serious disabilities for the child.

Did You Know?

Birth defects can have life-long costs. In the United States, birth defects have accounted for over 139,000 hospital stays during a single year, resulting in \$2.5 billion in hospital costs alone.

Investing in Research. We are committed to learning as much as we can about birth defects and developmental disabilities through our surveillance and research programs. Our surveillance systems provide a snapshot of the prevalence of birth defects and developmental disabilities, and our research helps us understand the causes of and risk factors for these conditions. In 2009 we learned and reported the following:

- Maternal diabetes, specifically type 1 and 2 diabetes, has been associated with a wide range of birth defects; gestational diabetes has been associated with some birth defects. Significant disparities in maternal, infant, and fetal outcomes have been found in studies of pregnant Native-American women. **To better understand maternal diabetes, we are funding two pilot programs aimed at diet and exercise intervention to prevent gestational diabetes in Native-American women.**
- **Children from multiple births** in the United States have a greater risk for intellectual disabilities and a greater risk for cerebral palsy than those from single births.
- Medication use and exposure during pregnancy may occur among women who don't realize they are pregnant or among woman who regularly take medication for the treatment of a chronic medical condition. NCBDDD works to understand which drugs are safe to take during pregnancy. **Medicines recently found to be associated with an increased risk of birth defects include some antihypertensive medications, some antibiotics, and medications used to treat thyroid disease.** With this type of information, doctors can work with their patients to make the best decisions to protect both the mother and her baby.
- **Preterm birth is a major cause of infant death** and lifelong disability. Our researchers found that **birth defects were more than twice as common among preterm births** compared with term births; approximately **8% of preterm births had a birth defect.**

Working Together. It is impossible to do our work without the significant contributions of our many partners. It is equally impossible to capture all the examples of collaboration. Below are a few from 2009 that highlight our work in birth defects and developmental disabilities:

- **NCBDDD co-sponsored the 4th International Conference on Birth Defects and Disability in the Developing World along with the March of Dimes and the National Institutes of Health (NIH).** This conference brought together more than 400 world experts on birth defects prevention to discuss global strategies and opportunities in the prevention and treatment of birth defects.
- **To better understand the relationship between birth defects and later development of cancer,** we collaborated with the National Cancer Institute at the National Institutes of Health and CDC's National Center for Chronic Disease Prevention and Health Promotion to fund two sites linking data from birth defects surveillance systems to data from cancer registries.

The National Birth Defects Prevention Study has more than 33,000 families enrolled to identify preventable causes of birth defects. The study is exploring the role of maternal lifestyle factors, prescription medication use, chronic health conditions, and occupational and environmental exposures.

Did You Know?
Birth defects and pre-term births are leading causes of infant mortality in the United States.

Looking to the Future. It is our belief that the research and collaboration we have begun will yield breakthroughs for birth defects and developmental disabilities. We have outlined important activities for the coming year, some of which include:

- **Learning more about autism by gathering information** on risk factors, such as genes, health conditions, and maternal exposures as well as health and developmental factors during the first years of life. This is a critical area given that **our new research shows that among 8-year-old children in the United States, an average of 1 in 110 have autism spectrum disorder.**
- **Expanding research to promote prevention and support the health and wellness of children and adults with congenital heart defects (CHDs).** Affecting nearly 1 in 100 infants, CHDs are among the most common birth defects. Our research has identified important risk factors such as obesity, smoking, gestational diabetes, and hypertension.
- **Supporting folic acid fortification** globally. Last year, our scientists supported and provided global health consultation to nine countries considering folic acid fortification. We will continue our global efforts which include promoting folic acid policies, fortification, quality control, and supplementation.
- Working with states **to track children identified through newborn screening to help them live longer and healthier lives.** Newborn screening can save lives by identifying dozens of health conditions, thereby providing opportunities for early intervention and coordinated care.
- Working with select **health departments to evaluate a model for training health care providers in Sexually Transmitted Diseases (STDs) and family planning clinics to deliver a motivational intervention for non-pregnant women who are at risk for an alcohol-exposed pregnancy.** Prenatal alcohol exposure is a leading preventable cause of birth defects and developmental disabilities.



Having a baby with a birth defect: A mom's thoughts

At 19 weeks of her second pregnancy, Julie Mayberry and her husband were excited because they were having an ultrasound to learn the sex of their child. They never imagined the test would reveal anything more dramatic; however, the Mayberrys were told their baby would be born with spina bifida.

The Mayberrys' daughter was born December 26, 2001. She is now 8 years old and has enjoyed "dancing" with the help of her wheelchair since the age of 3, inspiring other children with disabilities to dance as well.

"Do I wish she did not have spina bifida and could run and play like other children? Yes. But would I change who she is? No. She is beautiful and perfect in every way to me," says Julie. "Now, I am able to tell other women how important it is to take 400 micrograms of folic acid if you are able to get pregnant, even if you are not planning a pregnancy. If you've already had a child with a neural tube defect, it is recommended you take 4,000 micrograms of folic acid. That's what I did, and both of my other children were born healthy."

Assuring Child Health: Promoting Healthy Child Development

It is one of the most wonderful moments in a person's life: holding his or her baby for the first time. Parents naturally want to be able to meet all of their child's needs but sometimes face obstacles in doing so. CDC works to assure healthy beginnings for all children and to find ways to support parents in helping their children grow into healthy, safe, productive members of society.

Impacting Lives. Every day, we work to learn more about how to help children reach their full potential through research, interventions, and providing important health information. Below are a few examples of accomplishments in 2009:

- Working with partners, **we have been successful in screening more than 94% of babies born in the United States for hearing loss through our Early Hearing Detection and Intervention (EHDI) program.** NCBDDD estimates show that early hearing screening and intervention can save approximately \$200 million in additional educational costs each year.
- **Data from a nationally representative sample of U.S. children revealed that 3 out of every 1,000 children** between the ages of 6 and 17 in the United States have been diagnosed with **Tourette syndrome (TS).** The study found that a TS diagnosis is three times more common in boys than in girls and is about twice as common in children between 12 and 17 years of age as those aged 6–12 years.
- **We released the first evidence-based intervention guidelines for people living with fetal alcohol spectrum disorders (FASD), which result from prenatal exposure to alcohol and can mean lifelong, serious disabilities.** For many years, treatment plans for people with FASDs were based on practical wisdom gained by parents and clinicians through trial and error. Now, we can offer a fact-based intervention framework empowering parents, schools, social services, and mental health providers with information that can help those impacted by FASD. Also, we **released guidelines for clinical diagnosis of FASD since these disorders are traditionally difficult to diagnose.**

ADHD is a neurobehavioral disorder that affects an estimated 4.4 million school-age children and can last into adulthood. Improvement in the health of individuals with ADHD could result in substantial financial savings to families and society, potentially impacting the \$31.6 billion in excess costs associated with health care and work absences in children and adults with ADHD and their family members.



Investing in Research. We are committed to working toward healthy beginnings for all children and assuring they have an opportunity for living to their full potential. Here are a few examples of important surveillance and research activities in 2009:

- **An ongoing research project with the University of Colorado will collect and report developmental outcomes of infants and children identified through hearing screenings.** The project, being piloted in five states, aims to come up with a new data management system that can be used more broadly to gather this valuable information on the EHDI program.
- Among new mothers, 10–15% will experience major postpartum depression in the first several months after delivery, and debilitating symptoms can persist up to 2 years. Unfortunately, mothers often neglect their own primary care visits, and depression frequently goes undiagnosed. **NCBDDD is working with the American Academy of Pediatrics (AAP) and Boston Medical Center on a two-year study to look at the effectiveness of screening for maternal depression in pediatric settings.**
- Findings from a pilot study on spina bifida could eventually be used to determine when and if it would be beneficial to screen children with spina bifida for certain developmental, health, and education-related problems. **Working with the Spina Bifida Association, we collect information on patients treated in its national network of clinics and use the data to improve the care of children with spina bifida and provide a foundation for future research.**

Working Together. It is impossible to do our work without the significant contributions of our many partners. It is equally impossible to capture all the examples of collaboration. Below are a few from 2009 that highlight our work in promoting healthy child development:

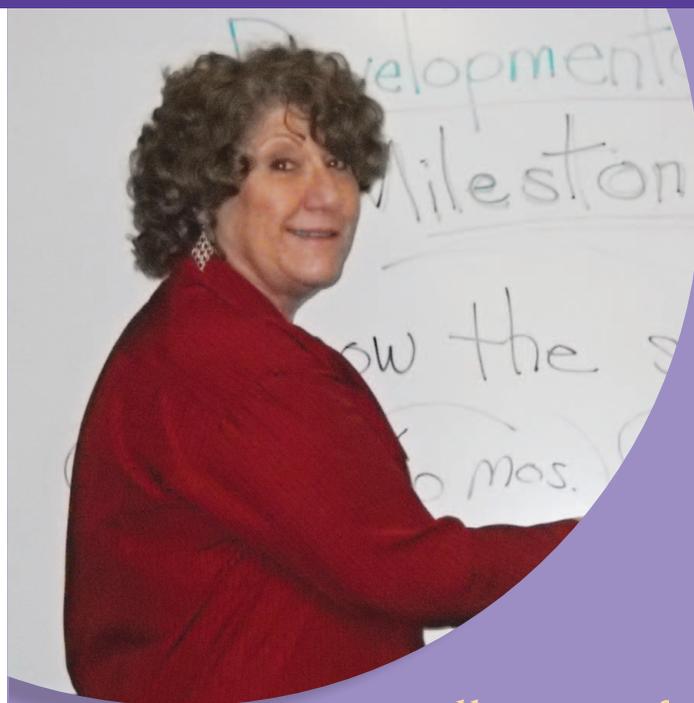
- **We have worked with national and international partners to develop, disseminate, and implement care considerations for the treatment of Duchene muscular dystrophy (DMD),** a condition characterized by progressive muscle weakness which affects about 1 in every 3,500 male births.
- **We partner with the National Resource Center on Attention-Deficit/Hyperactivity Disorder, which is the only national clearinghouse dedicated to sharing evidence-based information about identification, support, referral, and treatment for ADHD.** The National Resource Center promotes the health and well-being of children and adults with ADHD by fielding more than 12,000 inquiries and 1.1 million hits on its website each year.
- **NCBDDD is collaborating with CARE, Emory University, UNICEF, Bernard Van Leer Foundation, and the United States Agency for International Development** to design and implement a comprehensive model for improving early childhood development among orphans and vulnerable children in sub-Saharan Africa.



as 13% of children in the United States have a developmental disability which includes ADHD, autism spectrum disorders, cerebral palsy, hearing loss, intellectual disabilities, vision loss, and others.

Looking to the Future. It is our belief that the research and collaboration we have begun will yield breakthroughs for healthy child development. We have outlined important activities for the coming year, some of which include:

- Collaborative work with state EHDI programs, the Health Resources and Services Administration (HRSA), and other partners to **ensure infants receive recommended follow-up diagnostic and intervention services in a timely manner to realize the benefits of newborn hearing screening.**
- **Working with partners and professionals to help widely disseminate both the FASD guidelines for diagnosis and the evidence-based intervention guidelines for treatment of people living with FASDs.** Widespread sharing and adoption of both should have a tremendous impact on the accurate identification and treatment of people with FASDs.
- **Working with states to promote early identification and link services to better serve individuals and families affected by autism.** Through our ongoing collaboration with HRSA and the Association of University Centers on Disabilities (AUCD), our “Learn the Signs. Act Early.” campaign informs and connects health care providers, parents, early educators, early intervention coordinators, and others to promote child development.
- **Providing targeted health information to families of children with developmental disabilities** with the overall goal of promoting improved development and quality of life for children with disabilities and special health needs and their families.



College professor uses campaign materials to inspire future early educators

As a seasoned parent, early childhood educator, and community college professor, Estelle Flank has sharp instincts about child development. She credits CDC's "Learn the Signs. Act Early." (LSAE) campaign with giving her the tools she needs to help her education students develop their instincts too.

The LSAE campaign has been a key part of Estelle's curriculum. In fact, as part of her Child Growth and Development course, she required her students to visit the campaign website and order materials. "It is important to me that they learn how to access information about developmental milestones and know what valuable resources are available to them – and to parents."

Because early educators spend many hours observing young children, Estelle believes they are in a unique position to recognize potential developmental delays and refer parents to early intervention services. The campaign materials have armed her students with the information and confidence to reach out to parents and start the conversation about developmental milestones.

Improving the Health of People with Disabilities

One in five Americans – or 20% of the U.S. population – is affected by some type of disability. Although advances in medical care, technology, and rehabilitation have led to longer lives for people with disabilities, disparities in their health and quality of life persist. At CDC, we strive to help people with disabilities live healthy lives and participate fully in society. We are working to learn more about how health risk behaviors and chronic conditions impact people with disabilities. Our priority is to improve the health of all people with disabilities, and we are beginning to make progress in key areas such as improved health care access, community accessibility, healthier lifestyles, and emergency preparedness.

Impacting Lives. Every day, we are working to learn more about how to promote healthy living for people with disabilities. Below are a few examples of accomplishments in 2009 that touch the lives of people with disabilities:

- **Working with other national disability organizations, NCBDDD developed and distributed information on 2009 H1N1 influenza for people with disabilities and their caregivers/personal attendants.** Because people with certain types of disabilities have a higher risk for getting flu-related complications, this information emphasized actions to avoid the flu, including vaccination and personal infection control as well as treatment recommendations. In addition, NCBDDD played a critical role in linking the disability community to important public health services.
- **To address health disparities, NCBDDD funds 16 state-based programs with the goal of improving health, well-being, independence, productivity, and full participation in society among people with disabilities.** For example, Iowa is partnering with communities to conduct health promotion workshops for adults with physical disabilities, and Florida is training health care professionals to provide quality care for people with disabilities. State-based efforts continue to address disability as a public health issue and the inclusion of people with disabilities in public health programs that help to improve quality of life.
- **NCBDDD collaborates with the Special Olympics on its global Healthy Athletes program.** During Healthy Athletes events, Special Olympians receive health screenings and services in a fun, welcoming environment. In 2009, 856 screening events were conducted, and 192,600 individual athletes received health screenings around the world.

Did You Know?

According to a recent CDC analysis of data from the 2008 Behavioral Risk Factor Surveillance System, obesity rates are about 57% higher and smoking rates are about 62% higher for people with disabilities than for people without disabilities.



Investing in Research. Informed by our public health work related to the health of people with disabilities, we now understand that there are significant disparities in health status between people with and without disabilities. We also understand that the preventive health care needs of people with disabilities often go unmet, resulting in medical complications that may require hospitalizations. In 2009, important research activities in the arena of disabilities included:

- **Beginning development of a Web-based surveillance application to make available data on the health status and risks of the millions of adults who experience disabilities.** This application would allow users to view data from CDC's Behavioral Risk Factor Surveillance System (BRFSS) and assess the health of people with disabilities compared to those without disabilities. Users would be able to search numerous health indicators (e.g., smoking, obesity, blood pressure, etc.) across various demographic groups (e.g., age, gender, race, etc.) and geographic levels (overall, census region, census division, state).
- **Publishing research results that indicate people affected by spina bifida averaged 0.5 hospitalizations per year.** There were 22.8 inpatient admissions with urinary tract infection (UTI) per 1,000 patients with spina bifida, compared to an average of 0.44 admissions with UTI for patients without spina bifida. If the number of UTI hospitalizations among people with spina bifida were reduced by 50%, it is expected that expenditures could be reduced by \$4.4 million per 1,000 patients.

Working Together. As we aim to improve the lives of people with disabilities, NCBDDD has formed relationships with many organizations doing meaningful work in the field. It is impossible to do our work without the significant contributions of our many partners. It is equally impossible to capture all the examples of collaboration. Below are a few from 2009 that highlight our work in support of people with disabilities:

- **We support the National Center on Physical Activity and Disabilities (NCPAD) at the University of Illinois at Chicago.** The Center's mission is to increase physical activity among people with disabilities so that they can reap the health benefits of exercise. In early 2009, more than 700 people with disabilities signed up to receive weekly tips from a virtual trainer to keep them on track with fitness goals. NCPAD also distributes a free newsletter to more than 32,000 subscribers.
- **In partnership with rehabilitation centers, hospitals, and disability organizations such as the Christopher and Dana Reeve Paralysis Resource Center,** we are working to improve the long-term health and self-sufficiency of people with paralysis. According to a study initiative by the Christopher and Dana Reeve Foundation, there are nearly 1 in 50 people living with paralysis in the United States – that's about 6 million people.

A 2009 study co-authored by CDC researchers found that almost 27% of U.S. adult health care spending was associated with disability, amounting to \$397.8 billion in 2006 alone.

Looking to the Future. As veterans return from conflict and our nation continues to age, the number of people with disabilities will grow. CDC is working to address the 2007 Institute of Medicine recommendations on the health of people with disabilities, which call for investing in comprehensive disability monitoring systems and research, supporting public and professional education, and addressing health care accessibility and health promotion. We have outlined important activities for the coming year, some of which include:

- **Expanding our existing state-based disability and health programs from the current 16-state network and evaluating their effectiveness to help improve the health of people with disabilities.** This can help reduce health disparities between people with and without disabilities in key areas such as physical activity, smoking, and access to preventive care.
- Collaborating with other organizations to **coordinate health surveillance of adults with intellectual disabilities.** Currently, no comprehensive monitoring system exists for this population.
- **Preventing infections among people with disabilities through health promotion,** training, and improving their access to basic clinical and preventive services. People with mobility limitations, for instance, are more susceptible to secondary conditions such as pressure sores, respiratory infections, and urinary tract infections that lead to hospitalizations and lost productivity.



June knew she was at higher risk for breast cancer

because her maternal grandmother had the disease. She wanted to get screened, but the process proved more difficult for her than for most women. That's because June was born with cerebral palsy. Early on, a doctor suggested she get a psychological evaluation because she couldn't stay still for a mammogram. She had to explain it was her physical disability that kept her from staying still. She finally found a provider who listened to her, and she stayed with him for many years.

June, who was diagnosed with breast cancer in 2002, encourages other women with disabilities to be vigilant about screenings because early detection can mean the difference between life and death. "If you value your life and your health and you'd like to be around for a long time, it may not be easy," she said. "It may take more energy, but it's worth it."

Protecting the Health of People with Blood Disorders

Blood disorders affect millions of people each year. At CDC, we are working to improve the lives of all people living with blood disorders. These conditions, such as hemophilia, deep vein thrombosis (DVT), and sickle cell disease (SCD), can mean repeat hospitalizations, painful and expensive complications, and even death. We aim to prevent premature death and disability associated with many of these disorders through research, surveillance, health education, and outreach.

Impacting Lives. Blood disorders cross the boundaries of age, race, gender, and socioeconomic status. Men, women, and children of all backgrounds are at risk for, or living with, complications associated with these conditions. NCBDDD uses a population-based approach to set our path toward preventing and reducing the complications associated with blood disorders. Below are a few examples of accomplishments in 2009:

- NCBDDD supported a multi-site study of women with bleeding disorders and heavy menstrual periods to evaluate the effectiveness of hemostatic medications (designed to prevent clots from dissolving). **The study demonstrated that these medications were effective in decreasing menstrual blood loss and improving quality of life.**
- NCBDDD funded nine community-based organizations to provide credible health information and education for people with blood disorders. **Through this effort, national and local health promotion programs have been conducted to help over 12,000 people living with a blood disorder make informed health decisions.**

- A recent study found that children with sickle cell disease incur frequent emergency department visits and hospital stays, and many also experience complications or require regular blood transfusions. **During 2005, medical expenditures for insured children with sickle cell disease averaged \$12,000–\$15,000 per year.**



Along with other federal agencies and national professional and consumer organizations, NCBDDD co-led the development of a new focus area and objectives on blood disorders and blood safety for Healthy People 2020.

Investing in Research. Investing in research is an important part of a public health approach to blood disorders. In order to change the landscape and create a more promising future for people with these conditions, NCBDDD invests heavily in groundbreaking research of both common and rare blood disorders. In 2009, important research activities in the arena of blood disorders included:

- Supporting the Thrombosis and Hemostasis Centers Research and Prevention Network **to foster collaborative epidemiologic research designed to identify risks among the U.S. population and ultimately to improve early diagnosis and treatment of DVT/PE.** Funded centers have collected data on more than 5,000 patients of all ages and races while providing services to patients with DVT/PE and other thrombotic conditions.
- Developing of a national system to collect sickle cell disease (SCD) information and create registries at clinical sites to collect information about the health outcomes and impact of living with SCD. In partnership with the National Heart, Lung and Blood Institute (NHLBI), **this project will help determine SCD prevalence and identify risk factors for complications of one of the most common hereditary blood disorders in the United States.**

Did You Know?
 DVT/PE is associated with substantial morbidity and mortality: DVT occurs in up to 2 million people and PE claims about 300,000 lives annually in the United States – more than the total number of deaths from breast cancer, AIDS, and motor vehicle crashes combined.

Working Together. To make the promises of tomorrow a reality requires collaboration with health providers, health benefit plans, state health departments, and community-based groups. It is impossible to do our work without the significant contributions of our many partners. It is equally impossible to capture all the examples of collaboration. Below are a few from 2009 that highlight our work in support of people with blood disorders:

- Inhibitors are the number one blood safety issue for people with hemophilia. In response to a call from the Food and Drug Administration to identify risk factors for inhibitors, **NCBDDD has been collaborating with Baxter Pharmaceuticals and Wyeth Pharmaceuticals to conduct a pilot study with 12 U.S. hemophilia treatment centers (HTCs) to examine the feasibility of studying inhibitors through the Universal Data Collection (UDC) surveillance project.** An example of a successful private-public partnership, the results of this study could have implications far beyond hemophilia alone.

What is an inhibitor?
 About 10–15% of people with hemophilia develop an antibody (called an inhibitor) that inhibits the action of the clotting factors used to treat bleeding. Treatment of bleeding becomes extremely difficult because more clotting factor or a different type of clotting factor is needed.

- **In collaboration with the National Hemophilia Foundation, we developed the First Step Program for parents and families with newly diagnosed young children with bleeding disorders.** Promoted through hospitals, medical groups, and health care providers, this program provides education and support for parents of young children with hemophilia as well as training modules to help parents train and mentor others on the program.

Looking to the Future. Public health advancements in blood disorders will increase our understanding of their prevention and treatment. In recognition of this growing public health issue, NCBDDD is:

- Supporting the Thrombosis and Hemostasis Centers Research and Prevention Network, **to collect patient samples and initiate new research protocols to study the causes of DVT/PE and its adverse outcomes** based on the 2008 Surgeon General's Call to Action recommendations for a coordinated plan to address this condition. Through another study, **NCBDDD is also evaluating the effect of genetic variations on the risk of DVT/PE among African-Americans and Caucasians.**
- Working with the American Congress of Obstetricians and Gynecologists (ACOG) to evaluate knowledge, attitudes, and practices related to the **diagnosis of blood disorders among women** and developing educational materials to address the findings. About 2 million women in the United States may have a bleeding disorder and not know it. Women with these conditions are at increased risk for complications and reduced quality of life.
- Working in partnership with the HRSA, NHLBI, and the American Society of Hematology to **hold a National Conference on Blood Disorders in Public Health** to develop a nationally recognized public health framework for promoting health and improving outcomes among people at risk for or affected by blood disorders.



Lynn Levitt had no idea what the awful pain in her right side was that awakened her in the middle of the night.

Over the course of the next several days, she became short of breath and noticed her right leg was severely swollen. Emergency room doctors concluded that she had a pulmonary embolism (PE) and multiple deep vein thromboses and admitted her to the hospital immediately. A few months after getting treatment for this bleeding episode, Lynn was diagnosed with a rare blood disorder.

“Almost two years after this life-altering event, my husband and I face the challenges of living with this disorder,” says Lynn. “We hope to help spread awareness about the many different types of blood clotting disorders by telling our story. Maybe we can be a comfort to others who have had similar experiences. Maybe we can help prevent them from happening at all.”