Blood disorders are a serious public health problem affecting millions of Americans, yet we don’t have an accurate picture of the real impact of these conditions. CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD) is uniquely positioned to reduce the public health burden resulting from these conditions by contributing to a better understanding of blood disorders and their complications. We ensure that information is accessible to consumers and health care providers. We encourage the use of information to inform actions that improves the quality of life for people living with or affected by these conditions.

Budget

Learn more about budget

Learn more about state funding

Accomplishments

- Launched a new database of more than 1,000 Factor IX (Factor 9) gene mutations reported to cause hemophilia B. The new database supplements CDC’s Hemophilia A Mutation Project (CHAMP), a database of more than 2,000 Factor VIII (Factor 8) gene mutations reported to cause hemophilia A. This information can be used to determine...
which hemophilia mutations may increase the risk of developing an inhibitor (antibody) which lessens the effectiveness of hemophilia treatment.

- Worked with partners to launch surveillance of inhibitors, a significant complication of treatment in hemophilia. Inhibitors will be monitored through centralized testing at CDC. NCBDDD’s blood disorders laboratory developed new methods to test patients as well as new ways to confirm the results. The surveillance will result in the first estimates of the incidence and prevalence of inhibitors among people with hemophilia in the United States.

- Worked to decrease death and disability from venous thromboembolism (VTE) through health education and outreach. NCBDDD launched an expert video commentary series on Medscape, titled Blood Clots and Long Distance Travel: Advising Patients. NCBDDD authored a chapter on blood clots and travel in CDC’s Yellow Book and presented a Public Health Grand Rounds, “Preventing Venous Thromboembolism,” which addressed what is known about how to reduce the rate of hospital-associated VTE.

- Published an investigation of a cluster of late vitamin K deficiency bleeding (VKDB) in infants. NCBDDD developed a comprehensive communications and outreach plan, developed a fact sheet, “Protect Your Baby from Bleeds - Talk to Your Healthcare Provider about Vitamin K,” created a podcast, “Talk with Expectant Parents about Late Vitamin K Deficient Bleeding Among Infants,” and released a Medscape Commentary on VKDB.
Protecting People and Preventing Complications of Blood Disorders
Annual Report | Fiscal Year 2013

- Convened an expert panel to get stakeholder feedback on gaps in prevention research across blood disorders and identify priority areas for intervention research, implementation, and evaluation. A summary of this meeting has been developed and submitted to a special supplement of the American Journal of Preventive Medicine.

- As a result of NCBDDD’s Registry and Surveillance for Hemoglobinopathies surveillance pilot project, California initiated population-based surveillance for thalassemia. A newly-established committee is using the surveillance data to create fact sheets that educate Californians about the incidence of thalassemia in their state.

- Launched a Blood Safety Surveillance System among people with blood disorders to identify complications and infectious transmissions in heavily transfused populations such as those with thalassemia and sickle cell disease to keep the blood supply safe for everyone.

Looking to the Future

NCBDDD’s Division of Blood Disorders is committed to serving those with inherited (hemophilia, thalassemia and sickle cell disease) as well as acquired (VTE) blood disorders. Collaborating with our many public health partners – other federal and state agencies, academia, and professional and community-based organizations – NCBDDD’s Division of Blood Disorders improves the lives of people at risk or affected by blood disorders. Emerging issues in each of our priority areas include ensuring that evidence-based interventions are put into practice to improve health outcomes for the populations we serve. For example, among people with severe hemophilia, the overall proportion of people regularly using factor

Did You Know?

- 60,000-100,000 Americans die of deep vein thrombosis/pulmonary embolism each year.¹
- Sickle cell disease affects an estimated 90,000 to 100,000 Americans.²
- A CDC study showed that people with hemophilia were at risk for developing an inhibitor, which is currently the most serious complication of hemophilia care.³
treatment products to prevent bleeding episodes (the only evidence-based prevention strategy for joint disease) rose from 34% in 2004 to only 45% in 2009 and it is estimated that fewer than 50% of hospitalized patients receive risk-appropriate prevention for VTE.

Notable 2013 Scientific Publications


Protecting People and Preventing Complications of Blood Disorders
Annual Report | Fiscal Year 2013

References


To view the annual report online, please visit:
http://www.cdc.gov/ncbddd/aboutus/annualreport2013

For more information, please visit:
http://www.cdc.gov/ncbddd