

policy impact

CSL Behring Public Policy Newsletter Q3 2010

CSL Behring Awards Four LEAD Grants to Support Patient Advocacy

Nearly \$50,000 provided to patient organizations to support grassroots advocacy

As part of its Local Empowerment for Advocacy Development (LEAD) program, CSL Behring recently awarded four advocacy grants totaling \$49,700 to patient organizations in the United States. LEAD Grants support grassroots advocacy efforts by organizations committed to helping people who use plasma-derived and recombinant therapies to manage rare and serious conditions. CSL Behring has awarded 27 grants for a total of \$402,400 since 2008.

The following organizations were most recently awarded a CSL Behring LEAD grant:

Platelet Disorder Support Association (PDSA) is using its grant from CSL



Behring to create four patient support groups, including an online support group for teens and a teleconference support group for young adults. The grant will also support the development of educational materials, speaker assistance and a toll-free number. PDSA is the nation's leading non-

profit health organization dedicated to supporting people with idiopathic thrombocytopenic purpura (ITP), a rare bleeding disorder that causes extremely low platelet levels.

"The LEAD grant enables PDSA to continue to support and expand our Peer Communication and Support Group programs, ITP can be a very isolating disease. Our support groups provide a forum where we can educate and advocate, and also offer ITP patients and families an opportunity to share their experiences. There is nothing more comforting than speaking with someone who understands your illness."

—Caroline Kruse, Executive Director of PDSA

Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) is using



TENNESSEE HEMOPHILIA
& BLEEDING DISORDERS FOUNDATION

its grant to launch a new program called *Optimizing Care and Choice Through Triple A: Awareness, Advocacy and Action*. The main objective of the program is to establish a grassroots advocacy initiative

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CSL Behring Public Affairs

CSL Behring is committed to educating decision-makers and impacting public policies that affect patient access to care. The company has an active public affairs group in the United States including Dennis Jackman, Sr. Vice President for Public Affairs; Patrick Collins, Director, Public Affairs; Kim Isenberg, Sr. Manager, State Government Affairs; and Ryan Faden, Manager, State Government Affairs. All four have extensive public policy backgrounds and work closely with affected stakeholders and political thought leaders to affect change. Please contact them with any questions you may have regarding public policy issues.

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in Tennessee for the bleeding disorders community where one did not previously exist. This program includes revising and updating the state Hemophilia Program, increasing the involvement of women with bleeding disorders as part of the advocacy initiative and creating Emergency Medical Service treatment guidelines for individuals with bleeding disorders.

“Due to many recent changes in state legislation, insurance coverage and the economy, it has become imperative that we develop and launch a structured advocacy program to meet the needs of the bleeding disorder community. It is our hope that this new initiative will result in an organized program with a clear, focused direction that can easily be replicated by other organizations to ensure growth and sustainability.”

—Mary Hord, Executive Director of THBDF

Rocky Mountain Hemophilia & Bleeding Disorders Association (RMHBDA) is using its grant from CSL Behring to develop the infrastructure for a grassroots advocacy program which will include customized advocacy training for RMHBDA’s Family Camp. The grant will also help fund research and development of an advocacy guide for Montana and Wyoming, and an advocacy page on the organization’s Website in addition to a statewide advocacy day.



“We are a small organization that serves Montana and Wyoming, across vast geographical distances. The LEAD funding will help us implement our advocacy program over both states and help us educate both members and policy makers about the needs of our bleeding disorders community.”

—Ann Schrader, Executive Director of RMHBDA

Central California Hemophilia Foundation (CCHF) plans to



use the grant from CSL Behring to establish a Hemophilia Advocacy Action Team composed of young adults. The grant builds on CSL

Behring’s *Raise Your Voice!* youth advocacy program by creating a team of six to ten young adults who will be trained on issues surrounding access to care, including both plasma and recombinant therapies. A mentoring program for this team will also be developed in concert with local legislators and state agency staff.

“The LEAD grant enables us to expand our future leaders program called the Hemophilia Advocacy Action Team. This program equips young people and expands their future opportunities, while also educating policymakers about the issues important to the bleeding disorders community.”

—Sean Hubbert, President of CCHF

Next LEAD Grant Application Deadline Is October 31, 2010

LEAD grants are awarded semi-annually. CSL Behring considers grant proposals which relate to coagulation disorders, immune deficiencies, hereditary angioedema, genetic emphysema or other conditions reliant on plasma-derived therapies including critical care and wound healing. The submission deadline for the next round of grants is October 31, 2010. Applications, specific criteria for applying and more information about the LEAD program are available at www.cslbehring.com/leadgrants.

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California Legislature Unanimously Approves Bleeding Disorder Standards of Care

Awaiting action by Governor Schwarzenegger

On February 8, 2010, California State Senator Fran Pavley (D) introduced the Standards of Service for Providers of Blood Clotting Products for Home Use Act (SB971). Thus began the long journey from bill to law.

SB971 establishes requirements for entities that provide blood clotting products for home use in the treatment of hemophilia, von Willebrand disease and other bleeding disorders. The legislation also designates the California Board of Pharmacy to administer and enforce these provisions. The provisions of the bill emanate from the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC) recommendation #188—Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders. The provisions are intended to help assure patient access to the care they need.

The Hemophilia Council of California (HCC) and the four local California bleeding disorder organizations have worked tirelessly to introduce the legislation and advance SB 971 throughout the legislative session. CSL Behring has partnered with the HCC in this effort. The patient advocacy organizations have brought together an enthusiastic, committed and persistent broad coalition of patients, families, doctors, nurses, social workers, manufacturers and volunteers. Because of their grassroots effort to educate lawmakers about bleeding disorders and quality patient care, this broad coalition along with Senator Pavley and her staff, can take credit for the legislation receiving unanimous support in both the California Assembly and Senate.

The overwhelming support might suggest that the bill has been met without opposition. On the contrary, SB 971 has been amended eight times (not uncommon in the



Sen. Pavley (first on left) and staffer Elise Thureau honored by the Hemophilia Council of California

legislative process) in order to address the concerns of groups that felt they may be adversely impacted by the new law. Senator Pavley, HCC and their Legislative Advocate, Terri Cowger-Hill were successful in removing opposition by working with those key opponents to find compromise language that was agreeable to all parties. Those compromises have helped to ensure the unanimous support that SB971 has received in six separate legislative committees and the full bodies of both houses.

As SB971 makes its way to the Office of Governor Arnold Schwarzenegger, all are hopeful that he will sign the bill and it will become law, also encouraging other states to take similar action.

Several other states and patient organizations have initiated efforts to have standards approved. In Pennsylvania, the state House of Representatives unanimously approved legislation and efforts are in place to have the Senate act before the legislature concludes its session. To date, New Jersey is the only state to approve, sign into law and implement standards of care for bleeding disorders.

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New Federal High-Risk Pools: A Prescription for the Uninsured?

For millions of Americans with pre-existing medical conditions, health insurance can literally be unattainable regardless of income level. These “uninsurable” individuals have sought coverage, but have been unable to purchase it in many cases because they have been rejected or because they have been offered coverage only at unaffordable premium rates. Because of their often complex or costly health conditions, uninsurable individuals constitute the segment of the broader uninsured population that most needs health insurance coverage in order to receive the care they need to lead healthy productive lives.

To aid these uninsurable individuals, 35 states implemented high-risk health insurance pools over the past three decades. However, these plans often did not provide adequate benefits for the individuals they were designed to serve. For example, some plans included onerous annual caps on treatment expenditures.

In an effort to combat this, the federal health reform legislation of March 2010—The Patient Protection and Affordable Care Act” (PPACA)—provided \$5 billion, dispersed among all 50 states for expanded programs run by states or by a designated insurer if they choose those options. Twenty-nine states and Washington D.C. had implemented such expanded programs as of July 31 while 21 states have deferred to the federal government to handle the new programs. These programs are collectively known as “Pre-Existing Condition Insurance Plans” (PCIP).

PCIPs will be in place until January 1, 2014 to provide coverage options for otherwise uninsurable individuals

pending the full implementation of PPACA. According to the Kaiser Family Foundation, PCIPs in general have received few applications to date but it is expected that more applications will be submitted once word spreads about the availability of the new options. Eligible individuals must meet the following criteria:

Citizen or national of the United States or otherwise lawfully present in the U. S.;

Has not been covered under creditable coverage (based on HIPAA provisions) during the six-month period prior to the date of application for coverage through the PCIP; and

Has a pre-existing condition, based on the presentation of documentation, for which the individual has been refused coverage, or has been offered coverage with a rider that excludes certain benefits associated with their condition.

The PCIPs are designed to mirror the benefits offered by Federal Employees Health Benefit Plans and cannot impose a coverage waiting period on eligible individuals. Additionally, premium rates may vary on the basis of age by a factor of not greater than four-to-one, and be established at a standard rate for a standard population. The bottom line is that premium rates will be indexed to the rates of individual plans in a given geographical area, which should result in more affordable plans for a broader segment of the population. Thus, the newly created high risk pools may provide a viable option for individuals utilizing plasma protein therapies who have faced difficulty in obtaining and/or maintaining insurance coverage over the years.

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Did You Know? *With the passing of Senator Robert Byrd, Representative John Dingell (D-MI) is now the longest currently serving member of Congress. Rep. Dingell has been in office for nearly 55 years.*

Daniel Inouye (D-HI) is the longest currently serving Senator, having been in office for 51 years.



Rep. John Dingell (D-MI) posing a question at a committee hearing.