Key Issues Dialogue: Standards of Care Legislation

Featuring Kathy Antilla, Val Bias, Jerry Powell, M.D., Ann Rogers, Patrick Collins and Kim Isenberg
From left: Kim Isenberg, Dr. Jerry Powell, Patrick Collins, Val Bias, Ann Rogers and Kathy Antilla
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About Standards of Care

State-based initiatives to introduce standards of care legislation ensuring access to plasma-derived and recombinant therapies, including necessary ancillary services, is growing in support across the country. These therapies include blood clotting factors, immune globulins and Alpha-1-proteinase inhibitor.

The Hemophilia Association of New Jersey was the first organization to successfully advocate for such standards and was able to pass legislation in New Jersey requiring standards for access to therapies and providers for patients with hemophilia. The New Jersey legislation was later endorsed as model legislation by the Council of State Governments.

Following New Jersey’s lead, standards of care legislation was introduced in other states in 2007. Currently, legislation is being pursued in both Pennsylvania and Minnesota while the Hemophilia Council of California will promote this initiative in the California legislature in 2008. In addition, Alabama Medicaid has adopted the New Jersey standards through regulation. Although each state’s legislation will be specifically tailored to meet their individual state needs; nevertheless, all forms of this legislation share the following overarching objectives:

- Establishment of standards for recognized home care pharmacies providing services to patients reliant on plasma-derived and recombinant therapies.
- Implementation of health plans requiring patient access to all recognized home health care coverage and services.
- Implementation of health plans requiring patient access to the array of FDA approved plasma-derived and recombinant therapies available on the market.
- Implementation of health plans requiring access to hemophilia treatment centers and to clinical laboratory services.
- Required screening for von Willebrand disease in cases of menorrhagia prior to a procedure such as a hysterectomy.

Recently leaders from patient communities in the United States met to talk about standards of care surrounding rare diseases such as bleeding disorders and immune deficiencies.

This dialogue is part of a series addressing healthcare-related topics, sponsored by CSL Behring for patients, caregivers and healthcare professionals in the communities we serve. To view the entire series online, visit www.cslbehring.com/dialogues.
The Challenge with Standards of Care

PATRICK COLLINS: For this dialogue, we’ve selected an issue that is really at the heart of access to care. We will be discussing standards of care legislative initiatives taking place across the nation. These initiatives address the challenges surrounding maintaining access to therapies and supportive services for people relying on plasma-derived and recombinant therapies. To start with, what are some of those challenges?

KATHY ANTILLA: Many persons diagnosed with primary immunodeficiency disease have antibody production defects and are unable to produce protective antibodies or develop immunity to help their bodies fight infections. Immunoglobulin replacement therapy is the only clinically proven treatment for this condition. It is life-saving and enables those individuals to live healthy and productive lives. There are many differences between the various brands of immunoglobulin that may have different implications for our patients. So it is imperative that patients have access to all brands of immunoglobulin in all sites of care, and a patient's standard product should never be switched based on cost without a physician's prior approval.

VAL BIAS: I think that’s a perfect illustration of why the legislation in Minnesota’s Standards of Care bill is so vital. Each brand is unique. There are different indications among the different brands. I think this also applies to blood-clotting factors as well.

DR. JERRY POWELL: To directly address the question about challenges to maintaining access, I think it all boils down to patients not being in charge. Patients need to be empowered to make choices that are in their best interest.

KIM ISENBERG: Kathy, your issues are very similar to those of the bleeding disorders community in terms of access to medicines and treatments. Do your patients, have nationwide access to identified Centers of Excellence staffed by healthcare professionals who understand primary immune deficiency and know how to treat it?

KATHY: Despite the excellent healthcare available in the United States, one of the biggest obstacles for persons diagnosed with primary immune deficiency diseases is access to a specialist who will provide them with optimal treatment. Even in metropolitan areas, it is often difficult to find a specialist. Unfortunately, there is a dearth of physicians being trained in the field of clinical immunology. In fact, some states have no clinical immunologists. Medical personnel and the general public are typically unaware that individuals experiencing recurrent, unusual and serious infections should be evaluated for primary immunodeficiency disease. According to the Immune Deficiency Foundation,
the average length of time between the onset of symptoms and diagnosis is 9.2 years. Patients suffer for years before receiving the correct diagnosis and, therefore, the right treatment.

**Standards of Care Bills in Progress**

**PATRICK:** The Standards of Care legislation allows us the opportunity to address many of these direct access issues. Kathy and Ann, you have been working on bills in Minnesota and Pennsylvania, respectively. Jerry and Val, you are working on a bill in California. Could each of you elaborate on what may be forthcoming in your states?

**KATHY:** We are just starting this process in Minnesota. In May 2007, the Minnesota Senate introduced S.F. 2290 which focuses on ensuring quality of care for persons utilizing plasma protein therapies. If enacted, this legislation would require that consumers have access to specialized laboratories with expertise in testing for conditions treated with plasma protein therapies; access to qualified, skilled home care providers; and screening for von Willebrand’s disease (VWD) prior to undergoing a hysterectomy for unexplained menstrual bleeding. This bill has been referred to the Committee of Health, Housing and Family Security. In February 2008, a partner bill will be introduced in the House of Representatives. When it is appropriate, we will ask our community in Minnesota to contact their legislators about this bill.

**ANN ROGERS:** In Pennsylvania, the process is further along. The two Pennsylvania chapters of the National Hemophilia Foundation initiated a grass roots effort in 2004 to address insurance problems in our statewide community of 1,700 patients treated at seven Hemophilia Treatment Centers of Excellence in Pennsylvania. With the support of the Hemophilia Treatment Program Medical Directors, we organized our patient community and introduced a Standards of Care bill with five key points. The first four points guarantee access to services for patients with bleeding disorders, including:

- Access all identified Hemophilia Treatment Centers in Pennsylvania;
- Access to all factor replacement therapies and medicines for the treatment of bleeding disorders;
- Access to the coagulation laboratories associated with our hemophilia treatment center network in Pennsylvania; and
- Access to options in pharmacy distribution and home supportive services if ordered by our physicians.

The fifth point relates to VWD. Prior to the authorization of an invasive uterine procedure, such as a hysterectomy, a woman with excessive bleeding would be
referred to one of the seven Hemophilia Treatment Center programs in Pennsylvania for screening for a potential bleeding disorder.

**KIM:** What was your strategy in advancing the bill?

**ANN:** We secured a sponsor for the bill who introduced it in the Pennsylvania House of Representatives. We met with individual legislators, the leadership in the House of Representatives and the Governor’s Office. We moved the bill through and out of Committee in our first round.

Unfortunately, our efforts were interrupted in the 2005-06 session by opposition from the Pennsylvania Insurance Federation, which represents major insurance companies. In addition, the Pennsylvania Department of Medicaid announced its intent to implement a preferred formulary for Medicaid patients. The preferred formulary would cover all diseases, including hemophilia. Hemophilia treatments would be offered as preferred products in order to contain costs. As a result, we redirected our focus to the Medicaid issue.

Teaming with the National Hemophilia Foundation, we added a media component to our strategy. Finally, in December ’05, the ruling came down from the state. Every disease would have a preferred formulary. And, for hemophilia, access to all products would be maintained. We were grateful.

**KIM:** What happened to the Standards of Care bill?

**ANN:** Although it was approved unanimously by the House Health and Human Services Committee, we were never able to move the bill to the floor of the House of Representatives for a full vote, although we knew we had the support for it. Therefore, we decided to stop the effort, to put it on hold until ’07 when we would reintroduce the bill in both the House and Senate. The reintroduced legislation is the Hemophilia Standards of Care Act, Senate Bill 1030 and the identical House Bill 1105.

**KIM:** Was this exactly the same bill as the one you introduced the first time around?

**ANN:** We shortened it. We tweaked it. But the Insurance Federation opposed it again. We, therefore, decided to place the bill with the committee that would have the strongest opposition to it, namely, the House Insurance Committee. We went directly to the most challenging group since we knew the bill would eventually end up there.

**KIM:** Where is the bill now?

*We believe if the bill passes it will probably save the state money since it costs money for patients to be required to try different medications and have their blood work unnecessarily repeated multiple times.*
In the late fall of ’07, we made a strategic decision to promote the bill after two public hearings, which were conducted by the chair of the House Insurance Committee. These hearings were held at two hemophilia treatment centers located at the University of Pittsburgh and at the Milton S. Hershey Medical Center—not in the state capital. We wanted those who question the legislation to tour the centers and see first hand where our patients were being treated. After the hearings closed, we took the bill to the House and directed it to the Pennsylvania Cost Containment Council.

The premise of the insurance industry is that if this bill passes, it will cost the Commonwealth of Pennsylvania money. As a result, the Pennsylvania Cost Containment Council is conducting a fiscal analysis often referred to as a cost-out to determine the total costs to the state, if any. In fact, we believe if the bill passes it will probably save the state money since it costs money for patients to be required to try different medications and have their blood work unnecessarily repeated multiple times. Furthermore, by receiving the appropriate therapy from the start, adverse events and bleeding episodes will be reduced as well as unnecessary hospitalizations. In the long-term, this legislation is bound to save money for both tax-payers and the insurance industry.

**Regional Differences**

**KIM:** Based on our understanding of the Pennsylvania legislation, how does the situation vary from state to state or region to region?

**VAL:** In California, not only is our legislation different, but also our patient organizational structure. We have four chapter organizations in California which fall under the Hemophilia Council of California. I’m the executive director of the Council, and we coordinate our advocacy agenda. We have legislative counsel to advocate on our behalf in Sacramento and monitor our budget process similar to Pennsylvania.

When I took over management of the Hemophilia Council in 2003, the state was just about to implement a new reimbursement system for clotting factor. California Medicaid had previously been using a reimbursement model that was resulting in the state being charged more than was appropriate. So, the state adopted a model based on the average sales price for a given brand of therapy, which is a good reimbursement rate for clotting factor products.

**KIM:** What effect did that have?

**VAL:** It had two effects. First, it stabilized the home care market, meaning all providers could participate in the market and knew they were going to get a reasonable reimbursement. And second, it opened up the market for Public Health Service
Hemophilia Treatment Centers to participate in the distribution of clotting factor. So, our issues were less related to access and more about how we would handle this open market of distributors, which included Hemophilia Treatment Centers and somewhere between 30 to 40 specialty pharmacies in the state.

We were very concerned about the quality of service that would be delivered—not just from specialty home care providers, but also from our Hemophilia Treatment Centers, which are typically University of California teaching facilities. Since the programs are different in administration and product delivery we wanted to ensure a consistent standard of service.

Furthermore, access to treatment centers is only an issue in California if you’re treated in the Kaiser system. Kaiser operates a separate HMO system throughout California that, we believe, covers about a third of the state residents, namely, 11 million people. Kaiser has split the state to northern Kaiser and southern Kaiser. We chose, therefore, to leave Kaiser out of this Bill.

**KIM:** What were your goals for Standards of Care in California?

**VAL:** Basically, our issues were twofold: one, to get standards of service, and two, to solidify the relationship between state agencies providing care for people with bleeding disorders and Hemophilia Treatment Centers, which serve as case managers. Patients may enter the system in one of three ways. A patient enters the system through California Children’s Services or MediCal (California Medicaid) based on need. Alternatively, anyone who has moderate to severe hemophilia, or other rare disorders, qualifies for the California Genetically Handicapped Persons Program (GHPP). This program has no financial parameters; an individual is qualified simply by disorder diagnosis—by having the disease.

**ANN:** In Pennsylvania, these seven identified programs receive in total 2.98 million dollars per year. This is a specific line item in the state budget every year.

**KIM:** Val, how does Pennsylvania’s HTC network compare with California HTC’s in terms of cost efficiencies?

**VAL:** Right now, the state out-of-pocket costs for hemophilia within the GHPP is $51 million funded from the general fund. The program pays for clotting factor, for annual visits, for drugs and for screening. The GHPP program is for adults only, individuals aged 18 and above. It covered about 423 patients last year. California Children’s Services and MediCal cover another 1,200 patients, which costs the state $100 million. The state of California doesn’t provide state funding to the treatment center network.
The Bill Process

**KIM:** Val, could tell us a little bit about the process that you’re going through to get the bill introduced?

**VAL:** At the Council level, we’re drafting a piece of legislation that’s modeled after Pennsylvania with the notable exceptions I’ve mentioned. We will distribute the draft to all the hemophilia treaters, all the home care providers and all the pharmaceutical companies and ask them to review it. Then, with Terry Cowger Hill, our advocate, and the folks involved in the state budget process, we will review all of the comments and see what to put in and what to leave out. It will be a completely open-ended process.

**ANN:** Definitely different from Pennsylvania where we said, “This is what we need.”

**VAL:** Hopefully, we can compromise and get most of what everybody wants in the bill.

**PATRICK:** The beauty about Standards of Care legislation is that it can be adjusted by the patient organizations on the ground in the different states. Hemophilia of New Jersey started with a core set of standards for providers of therapies. The New Jersey standards are being used as a model with the inclusion of VWD. The Minnesota legislation has even brought in other patient organizations by setting standards for other plasma-derived therapies. Val, you’re seeing the successes and failures that are taking place in morphing the bill in California. It’s really an adjustable piece of legislation.

**VAL:** What’s different in California is we’ve been working for several years to get an edge in this process by building a relationship with the Governor. When Governor Schwarzenegger was elected, he came to our community saying, “I want $7 to $9 million of savings or I’m going to start cutting your programs up.” And, a lot of people perceived that as a threat, but he was facing a huge budget deficit in California. I thought what he proposed was, in fact, reasonable given the recommended reimbursement level, which would generate millions of dollars of savings.

We tried to help him cut costs, and, at the end of the day, we achieved the $7 to $9 million in savings he wanted. We supported and encouraged renegotiating the manufacturer’s reimbursement contracts with the state for the units purchased. We worked with home care providers to accept the new reimbursement rate. The Governor's office was very grateful. Since 2004 we have not been threatened with budget cuts, and we have set the stage for this piece of legislation to be passed without much opposition.
ANN: And the insurance industry right from the beginning has been saying, “All mandates; all mandates.”

JERRY: Yes, and the legislators we have approached keep saying, “If it costs, we don’t want to hear anything more about it.”

ANN: And, we have responded by saying, “You’re exactly right. Mandates usually do, almost always, cost money. But, our needs are so different, with so few specialists involved, that if patients are managed through this identified system of centers, they will get what they need; and, therefore, it will save money.”

JERRY: But, that’s never been demonstrated; therefore, if the cost-out reports a savings it would simply be golden.

ANN: In fact, we’ve got it. Last month we asked national home care pharmacies that service patients with hemophilia in Pennsylvania if they had national outcome data demonstrating that if patients get what they need initially, their outcomes are better. They were able to provide us with data substantiating that patients with hemophilia have better outcomes when they get what they need, regardless of where they live. We will submit this to the Pennsylvania Health Cost Containment Council. The data shows a reduction in ER visits by people receiving proper access to care, factor replacement therapies and quality home supportive care. Simply put, patients do better if they can get the therapies they need, when they need them.

Costs and Data

KIM: Several points have arisen in our conversation, which we should address. The first pertains to separate indications. In particular, every therapy is different and people react differently to different medications. Dr. Powell, could you explain why this medical fact is important to the bill?

JERRY: Of all the plasma-derived therapies, IVIg is the most complex because it contains the most proteins. Therefore, IVIg brands are not generic. As you move from IVIg to monoclonal antibody purified clotting factors to recombinant clotting factors, the product has fewer non-essential proteins. If you reference a specific protein the product can be defined reproducibly. Because of the complexity of the preparations, individuals respond differently to different IVIg preparations or for that matter to different plasma-derived therapies.
VAL: Yet because of the small population size for hemophilia we have not yet proven that clinically. We know anecdotally that it’s true and that’s how we treat our patients. But, we don’t have any clinical science that says there’s a real difference between one product and the other based on some long-term study encompassing 50 million patients. We don’t have such a study for hemophilia therapies or primary immune deficiency therapies. That’s part of the problem in dealing with insurance companies today. It’s all about data. We have had really great discussions with Blue Cross of California, which merged with Well Point, around why different treatment options are important. And, they have agreed with us. But this is a data-driven culture. Insurers want us to be able to prove these things.

JERRY: And, in order to do that, you need hundreds of thousands of patients. Big pharmaceutical companies can do that with their blockbuster drugs that treat common conditions. But there’s just no way that we will ever be able to do that with a rare disorder like hemophilia. Without data, insurers can take the high ground and say, “You have no data. So, you can’t talk to us.” It’s an argument that I find disingenuous.

KATHY: One of the strengths of the Immune Deficiency Foundation is the data obtained from patient, physician and pharmacist surveys. As a result of this collected data, legislation has been developed to improve access and reimbursement of all brands of immunoglobulin in all sites of care at the federal level. IDF has been able to move forward and work with insurance companies and Medicare because they have provided reliable, accurate data.

PATRICK: With these anecdotes, you are talking about cost savings. If the Standards of Care bill is a quality of care bill, and if we can provide statistical evidence that patients who are appropriately treated go to the Emergency Room less then the outcome will be cost savings.

Thinking Globally

KIM: What global issues come to mind when you consider Standards of Care legislation?

VAL: Two things come to mind for me. One, if you look at the pipeline of new biologics, there are about 150 biologics that will enter the market in the next five to 10 years. These products will be injectables, and they’re going to be expensive. They’re going to treat a lot of disorders beyond hemophilia and immune deficiencies. Insurers are desperate to find a way to control these drugs, which have to be administered either at home or in a physician’s office. And two, the only test market they have for controlling those kinds of drugs is with hemophilia and immune deficiencies.
But not one of the national patient organizations has actually had a candid discussion with the insurers, with the payers at a national level. We need to educate insurers about bleeding disorders and immune deficiency. We need to explain how it should be treated. I think this is the missing link in these bills.

**KIM:** What suggestions do you have about making those national meetings and interactions happen?

**VAL:** I’ve been trying to coordinate meetings through the Bias Group, the other part of my consulting business. I would like to initiate leadership forums by inviting guest educators to start a dialogue with the bleeding disorders community. A similar forum could be created for immune deficiency as well.

**KIM:** Would you suggest putting together a national forum, such as “Voices of the Communities,” maybe consisting of just these two communities and the twelve major payers in the United States?

**JERRY:** I think the problem is that the major insurance payers are such huge companies and hemophilia is such a small cost to them. You’re not going to get the top leaders to come.

**VAL:** Actually, I approached an insurance company about this concept. And they gave me a list of exactly who should attend the meeting.

**PATRICK:** Hemophilia and immune deficiencies comprise very small patient populations, but they are treated with expensive therapies, which may be near the top of the list in terms of overall cost an insurer may spend in a particular state or region. So, I think there may be interest there.

**How Can the Plasma Industry Help?**

**KIM:** How can industry be part of the effort to advance standards of care?

**KATHY:** Industry knows all the players. Perhaps they could help initiate the effort.

**ANN:** Over the past few years, the hemophilia community has worked with industry to obtain written endorsements for our bill and to access their knowledge base.

**VAL:** You may also want to consider who from industry should be involved in the process. I would like to put together a national council of government relations representatives. The council would be dedicated to strengthening reimbursements,
standards of service and standards of care. The council would advise us about convening a national forum for payers or initiating legislation.

**Beginnings of a Resolution**

**ANN:** As we work together on achieving our goals, could we, as a national community of patients, write down the top four things that we must have to live on this earth? What do we need? Then ask every doctor that treats us, "Do you agree with these four sentences?" Ask every manufacturer, "Do you agree with these four sentences?" Ask every pharmacist. Ask every legislator. Ask everyone. I’ll tell you what the four things are for me, and you tell me if you agree.

One, all patients in the United States need access to all FDA approved medicines and treatments. Two, patients with hemophilia or immune deficiencies need access to identified resources and specialized treatment. Three, we need access to specialized laboratories. And four, as a patient community, we need to have options in pharmacy distribution and home services.

**Standards of Care as Insurers See It**

**JERRY:** Let’s go back to something we touched on with Standards of Care. The big issue for insurers is they repeatedly say that mandates add to the cost of insurance and that’s why there are 43 million uninsured. If we say, “Standards of Care,” they hear “mandate.” In California, there are over 50 mandates that the insurance companies say add significant costs. So, we have to be careful in how we word this discussion especially as we plan to include insurers in our future discussions.

**ANN:** Jerry, you just touched on a major issue. In Pennsylvania, we actually changed the name of our bill when it was introduced the second time. We called it “The Hemophilia Standards of Care Act.” As a result, the Insurance Federation reflected, “Well, maybe this is a standard of care instead of a mandate.” Previously, we had called it “The Hemophilia Health Care Act.”

**VAL:** Yet, a standard of care doesn’t really exist in hemophilia because your own standard of care is based on what your physician at your hemophilia treatment center believes to be the best care for you. This is why in California our legislation will be a standards of service bill.

**JERRY:** The phrase “standards of service” is preferable to “standards of care” on two counts. First, in healthcare the phrase “standards of care” has a legal connotation, which should be used circumspectly. Second, standards of service are patient-focused.
As such, they can be structured to let patients choose what they consider to be optimal healthcare.

**About Centers of Excellence**

**KIM:** What defines a center of excellence?

**ANN:** The Centers for Disease Control in 1974 set up a nationwide system of hospital programs, dedicated to treating patients with bleeding disorders, primarily hemophilia. In exchange for federal support, the centers would provide surveillance that would chart important information about the health of a community that at the time was reliant solely on products made from blood. This standard model of care was consistent across the United States and came to be called centers of excellence. Therefore, a hemophilia patient would be treated in the same way in California as he would be in Pennsylvania. We now have an evolved system of medical management that I think is fantastic.

**JERRY:** There are approximately 145 hemophilia treatment centers in the United States. These centers form an informal network through which they communicate standards of service or standards of care.

**Screening for von Willebrand Disease**

**KIM:** The legislation in Minnesota includes a mandate on screening for VWD. How do we work with the physician community to build the support for keeping that component?

**ANN:** I’ll tell you how we approached it in Pennsylvania. The Centers for Disease Control (CDC) has followed our hemophilia patients since 1974. The CDC estimates that there are 30,000 unnecessary hysterectomies performed on women in the United States each year. Of these 30,000, some women may have a bleeding disorder such as VWD. Rather than just authorize payment for a hysterectomy when a woman presents with chronic excessive menstrual bleeding, we want to screen for a bleeding disorder.

**JERRY:** That could be interpreted as a mandate.

**ANN:** It is, in our bill.

**VAL:** I expect that we will run into some resistance with the California Medical Association around VWD. They’re going to see it as a mandate. We will have a preliminary discussion with them to understand their reticence. Then we will arrange a second meeting with their key stakeholders. But, when we go into that second
meeting, to my left will be leading California legislators and to my right will be representatives from offices of the speaker of the House, Nancy Pelosi; Senator Diane Feinstein; Senator Barbara Boxer and the leading women’s groups of the state. So, if the Association says, “No;” they’re not saying “No” to us. They’re saying “No” to every major woman’s group in California.

N.B.: On February 7, 2008, the California Commission on the Status of Women in partnership with the California Women’s Legislative Caucus held an informational hearing on VWD.

JERRY: This is similar to what we went through 25 years ago when hemophilia was being treated in the Emergency Room. There were talks back then of requiring, mandating by law that the Emergency Rooms treat hemophilia quickly and then take care of other medical problems. That never happened. We, as a medical community of hematologists, worked independently to help our hemophilia patients. We taught them when and how to self-administer clotting factor. In this way, our patients became more self-reliant.

ANN: In Pennsylvania, we had some initial rumblings from the Pennsylvania Medical Society. As a representative organization for physicians, the concern was raised that if a mandate is not followed then their members could be sued. So we gave them alternatives. For us, we changed the name—a lot’s in a name. Maybe “standards of service” is better than “standards of care.”

Advisory Boards: a Good Idea?

KIM: A few states have introduced legislation creating Advisory Boards that would advise the Department of Health and the Department of Medicaid on issues specific to bleeding disorders. Could you share your perspectives on this issue?

ANN: It’s all part of the healthcare pie—providing consumer or physician input to decision makers at the state level. In Pennsylvania it was never mandated. We are thinking of reinstating an advisory board as an adjunct to our bill.

PATRICK: Illinois just passed legislation reinstating a hemophilia advisory board.

VAL: In California, we have the Council. We have access to the budget people in the state process. We have a working relationship with the State agencies that has primary responsibility for the care of people with bleeding disorders. An Advisory Council would just get in the way of our current relationships. It’s all about relationships. It’s all about education.
As a company, CSL Behring supports patient organizations. We, therefore, support their decisions as to whether a standard of care initiative, an advisory board or both would be appropriate for a given state. It’s not our position as a company to say, “You should do this. You should do that.” CSL Behring would, therefore, endorse and work with any patient organization to implement either of these two initiatives in a given state.

In closing, we are faced with critical issues affecting patient populations and access to care. How should we address these issues? The legislation being proposed in Minnesota, Pennsylvania and California would help. It would expand access to care, access to treatment and access to the therapies that work best for each individual. The legislation in California, Minnesota and Pennsylvania would also serve as a model for other states to emulate, similar to the initial New Jersey legislation.
About the Participants

Katherine Antilla

Katherine Antilla is the director of education and volunteer programs at the Immune Deficiency Foundation (IDF), the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. Prior to accepting a position at IDF, Ms. Antilla was a special and elementary educator and worked on behalf of persons with primary immunodeficiency diseases as an IDF volunteer, a member of the IDF Board of Trustees and the International Patient Organisation for Primary Immunodeficiencies (IPOPI) Executive Committee. She has a Bachelor of Science degree from the University of Minnesota-Duluth and a Master of Arts in Education from Hamline University. Katherine became a tireless patient advocate for persons with primary immunodeficiency diseases after her son, Isaac, was diagnosed with common variable immunodeficiency disease in 1997. Since accepting a position at IDF, Katherine is now able to devote more time to her passion which is educating others about primary immunodeficiency diseases.

Val D. Bias

Val is executive director of the Hemophilia Council of California (HCC), a non-profit dedicated to improving the quality of life for all persons affected by coagulation disorders and related complications. The HCC promotes and ensures the welfare of all local California hemophilia consumer organizations. Val is also managing consultant for The Bias Group, which was created to address the special needs of philanthropy, industry, and research as they relate to advocacy and the chronically ill individual. He is also co-founder of Compass Nonprofit Consulting Services, which provides support to nonprofit organizations serving chronically ill patients.

Val has severe factor IX deficiency, and has been serving the bleeding disorders community since the late 1980s. He was the first African American Chair of the National Hemophilia Foundation (NHF) Board, the first Co-chair of the Men’s Advocacy Network (MANN) of NHF (a national Peer Education Program), as well as the Chair of the NHF Blood Safety Working Group. Val also served as legislative coordinator for the National Hemophilia Foundation from 1994 to 1998, and was responsible for the establishment of a national grassroots network. His leadership helped result in the passage of the Ricky Ray Hemophilia Relief Fund Act Public Law 105-369 in 1998.

Val currently serves as a member of the FDA’s Transmissible Spongiform Encephalopathies Advisory Committee (TSEAC), and runs the nationally recognized “Camp Hemotion,” the Hemophilia Foundation of Northern California’s residential Youth Summer Camp Program.

Jerry S. Powell, M.D.

Jerry S. Powell, M.D. is director of the Division of Hematology and Oncology and of the Hemophilia Treatment Center at the University of California, Davis Medical Center. Dr. Powell is also a professor of medicine, hematology and oncology at the University of California, Davis. He is board certified in internal medicine, oncology and hematology.
About the Participants

and is a member of the American Heart Association, American Society of Hematology, Hemophilia and Thrombosis Research Society, Western Society for Clinical Investigation, and International Society on Thrombosis and Homeostasis. Dr. Powell received his undergraduate degree from Stanford University and his medical degree from the University of Washington, Seattle. He completed his internship and residency at the University of Chicago and his fellowship in hematology and oncology at the University of Washington, Seattle. Dr. Powell is the recipient of numerous academic awards and honors.

Ann E. Rogers

Ann E. Rogers is the executive director of the Delaware Valley Chapter of the National Hemophilia Foundation located in Glenside, Pennsylvania. The Chapter represents 1,700 patients in southeastern Pennsylvania and the state of Delaware affected by bleeding disorders. Ann served as the president of the Chapter Staff Organization (CSO) of the National Hemophilia Foundation (NHF) from 2001-2007, representing the NHF member Chapters in the United States, including Guam and Puerto Rico.

Ann is the mother of three sons, two with hemophilia. Her oldest son, Daniel died at the age of 16 in 1992, due to the complication of AIDS, contracted through the use of contaminated blood clotting factors. Ann has worked for almost thirty years in local and national leadership roles, advocating for the bleeding disorders community. Ann holds a Master of Science degree in Speech Pathology and Audiology.

Patrick Collins

Patrick Collins is Sr. Manager for Public Affairs at CSL Behring. Prior to joining the company in 2001, Patrick served as Director of Government Affairs at the National Hemophilia Foundation. He has also served as a liaison to the New York City Council for a city agency in the administration of Mayor Rudolph Giuliani and was on the staff of a New York State Senator. Patrick can be reached at patrick.collins@cslbehring.com.

Kim Isenberg

Kim Isenberg is Manager for State Government Affairs at CSL Behring. Prior to joining the company in June 2006, Kim served as a regional director for government affairs at PhRMA and as the Director of Public Affairs for the Metropolitan Council, the regional planning authority for the seven counties surrounding Minneapolis and St. Paul, Minnesota and was a policy assistant to the University of Minnesota Board of Regents. Kim can be reached at kim.isenberg@cslbehring.com.

About CSL Behring

CSL Behring is a global leader in plasma protein biotherapeutics. Dedicated to saving lives and improving the quality of life for patients with rare diseases worldwide, the company provides safe and effective plasma-derived and recombinant products and offers patients a wide range of related services.
From left to right: Patrick Collins, Ann Rogers, Val Bias, Kathy Antilla, Kim Isenberg and Dr. Jerry Powell