

The logo features a red blood drop containing a white silhouette of a person and a child. To the right, the letters 'NHF' are in a grey, sans-serif font, and 'News Briefs' is in a large, bold, black serif font.

NHF News Briefs

January 6 – January 12, 2012

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This report includes selected news items from the past week on issues of concern to the bleeding disorders community. It is designed to help keep NHF national and local leadership and staff informed of the latest information from the news media. It will be distributed by email on Thursday of each week, covering important news items from the previous seven days. Subjects covered will include hemophilia, other bleeding disorders, thrombosis and thrombophilia, gene therapy, hepatitis, HIV/AIDS, and others.

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WFH appoints John Bournas as new CEO/ Executive Director

(Montreal, Canada) - The World Federation of Hemophilia is pleased to announce the appointment of John Bournas as CEO/Executive Director. Mr Bournas brings over fifteen years of senior managerial experience in the healthcare and not-for-profit sectors and international experience as a diplomat. His areas of expertise include management, business development, healthcare advocacy and cultivating relationships with stakeholders of the highest level of government. Mr Bournas will start his new position on January 25.

"The WFH is delighted to welcome John Bournas to our team," said WFH president Mark Skinner. "He brings a unique combination of skills and an international perspective that will be integral to achieving our strategic goals in the coming years."

Prior to joining the WFH, Mr Bournas was senior director of international affairs with the American College of Cardiology Foundation (ACC), the largest international professional society for cardiologists. He was responsible for global strategic planning, international memberships, partnering with national healthcare societies, global advocacy, and for diversifying the organization's revenue stream through engagement with its corporate partners. Before that, Mr Bournas was senior director-international with Cardinal Health in the U.S., a Fortune 19 company that specialized in improving the cost-effectiveness of health care.

Mr Bournas has also worked and travelled throughout the world developing relationships and bridging gaps between established and emerging countries. He worked as a diplomat in Chile, Australia, and Japan overseeing international trade and development projects. The son of Chilean and Greek parents, he was raised in Chile and the United States. He speaks Spanish, French, Portuguese, and some Japanese and Greek.

Mr Bournas holds a Master of Business Administration degree from Macquarie University in Australia, a Master of Arts in Political Science from Fordham University in the U.S., and a Bachelor of Arts in International Studies from Fairleigh Dickinson University in the U.S.

About the WFH

The World Federation of Hemophilia (WFH) is an international not for profit organization with member patient organizations in 118 countries and official recognition by the World Health Organization (WHO). It has been dedicated to improving and sustaining care for hemophilia and other inherited bleeding disorders worldwide since it was founded in 1963.

Sangamo BioSciences Announces Initiation of Two New Phase 2 HIV Clinical Trials
Studies Advance Development of a 'Functional Cure' for HIV/AIDS

(Richmond, Calif.) – Sangamo BioSciences, Inc. (Nasdaq: SGMO) announced today the initiation of two new Phase 2 clinical studies (SB-728-1101 and SB-728-902, Cohort 5) in its program to develop a "functional cure" for HIV/AIDS. Sangamo's ZFP Therapeutic® approach (SB-728-T) generates T-cells that are resistant to HIV infection using its zinc finger nuclease (ZFN) technology to permanently disrupt the DNA sequence encoding CCR5, a co-receptor used by HIV to enter cells. The company expects to present data from its SB-728-T HIV clinical trials at appropriate medical meetings in 2012.

"We are delighted to be able to open these two important clinical studies ahead of schedule," said Geoff Nichol, M.B. Ch.B., Sangamo's executive vice president, research and development. "Data from earlier Phase 1 trials demonstrated a statistically significant relationship between the number of circulating T-cells in which both CCR5 genes are modified and the reduction in HIV viral load in infected subjects during an interruption of anti-retroviral therapy. Both of these new Phase 2 clinical trials are specifically designed to confirm and further investigate these findings."

The new studies employ two approaches to increase the number of engrafted T-cells in which both CCR5 gene copies are modified (biallelically modified) in SB-728-T-treated, HIV-infected subjects. The first, an extension of an ongoing trial (SB-728-902, Cohort 5), is designed to further investigate the effect of SB-728-T treatment on HIV viral load in subjects that are naturally heterozygous for the CCR5 delta-32 gene mutation (i.e. one of their two CCR5 gene copies has the mutation and one is normal). The second study (SB-728-1101), in HIV-infected subjects without the CCR5 delta-32 mutation, employs a conditioning pretreatment designed to significantly enhance the number of engrafted biallelically modified T-cells.

The rationale for the Phase 2 studies is based on data obtained in a Phase 1 trial of SB-728-T that demonstrated a statistically significant relationship between the number of engrafted biallelically modified T-cells and the reduction in HIV viral load in treated subjects. In this earlier trial, the viral load of an SB-728-T treated-subject decreased to undetectable levels during a scheduled treatment interruption (TI). This subject was heterozygous for the CCR5 delta-32 gene mutation, thus doubling the number of biallelically modified T-cells after SB-728-T treatment.

"We are focused on applying our ZFP Technology platform to develop novel therapeutics to address unmet medical needs," stated Edward Lanphier, Sangamo's president and CEO. "In addition to the rapid progress that we are making in our clinical program to develop a "functional cure" for HIV/AIDS, we are advancing our preclinical ZFP Therapeutic programs to engineer genetic cures for monogenic diseases including hemophilias and hemoglobinopathies such as sickle cell anemia. Sangamo enters 2012 with a solid cash position which allows us to aggressively pursue our goals while maintaining our historic control on cash burn. As such, we plan to end 2012 with at least \$60 million in cash. We look forward to providing further financial guidance for 2012 as well as an update on our clinical and preclinical programs and our corporate partnering activities on our fourth quarter and end of year 2011 call in early February."

Mr. Lanphier will also provide an update on Sangamo's ZFN Therapeutic pipeline and an overview of the Company's business strategy and objectives for 2012 during his presentation at the 30th Annual J.P. Morgan Healthcare Conference at 7:30 am PT, on Thursday, January 12, 2012. The presentation will be webcast and available at <http://investor.sangamo.com/events.cfm>.

About the SB-728-T Program

Sangamo is developing SB-728-T, a ZFN approach to the treatment of HIV/AIDS. In addition to the newly initiated Phase 2 studies, SB-728-T is being evaluated in an ongoing Phase 1/2 and two Phase 1 clinical trials to evaluate the safety and clinical efficacy of this approach in CD4+ T-cells. Sangamo's ZFNs are designed to permanently modify the DNA sequence encoding CCR5, a co-receptor that enables HIV to enter and infect cells of the immune system. Individuals carrying a naturally occurring mutation in both of their CCR5 genes (homozygotes), a variant known as CCR5 delta-32, have been shown to be resistant to HIV infection. Building on this observation, a study published in *Blood* in December 2010 reported an effective cure when an AIDS patient with leukemia, the so-called "Berlin Patient," received a bone marrow transplant from a "matched" donor homozygous for the CCR5 delta-32 mutation. This approach transferred hematopoietic stem cells (HSCs) from the bone marrow of the delta-32 donor providing a self-renewable and potentially lifelong source of HIV-resistant immune cells. After transplantation, the HIV patient was able to discontinue all anti-retroviral drug treatments, CD4 T-cell counts increased, and HIV viral load dropped to an undetectable level, demonstrating effective transplantation of protection from HIV infection.

About SB-728-902 Cohort 5 – Phase 2 Study

Up to 20 HIV-infected subjects heterozygous for the CCR5 delta-32 mutation (i.e. with one CCR5 gene that is naturally modified) who are currently on Highly Active Anti-retroviral Therapy (HAART) will be enrolled and will receive a single intravenous infusion of SB-728-T (5 to 30 billion modified cells). Two months after SB-728-T treatment, subjects will undergo a 16 week TI during which time their anti-retroviral therapy will be discontinued. HAART will be reinstated in subjects whose CD4 T-cell counts drop to <350 cells/mm³ and/or whose HIV-RNA increases to >100,000 /mL for three consecutive weekly measurements. At the end of the TI, subjects with a sustained detectable HIV viral load will be reinstated on HAART. Subjects with an undetectable viral load will remain off HAART until HIV RNA levels are detectable or their CD4 T-cell count drops below 350 cell/mm³ for three consecutive weekly measurements.

About SB-728-1101 – Phase 1/2 Study

SB-728-1101 is an open-label, dose escalation, multi-center study designed primarily to evaluate the safety and tolerability of escalating doses of cyclophosphamide (Cytosan®) administered one day prior to SB-728-T infusion. Cytosan is a drug that is used to transiently reduce the numbers of T-cells in the body which then rapidly repopulate once the drug is discontinued. Such lymphodepletive treatment has been used to enhance engraftment of adoptively transferred T-cells in the treatment of cancer and as therapy for numerous autoimmune diseases. The drug has been previously used in HIV-infected individuals and studies demonstrate that, while the drug was

transiently lymphodepleting, it did not significantly reduce total CD4 T-cell counts over the long term and was adequately tolerated.

In addition to safety, the study will evaluate the effect of escalating doses of Cytosan on SB-728-T engraftment, the effect of SB-728-T treatment on viral load following HAART interruption, the change in CD4+ T-cell counts in peripheral blood and the long-term persistence of SB-728-T.

At least 9 HIV-infected subjects on HAART will be enrolled into 3 dose-escalating cohorts (3 subjects/cohort), and will receive intravenous Cytosan (200 mg, 500 mg or 1000 mg). Within each cohort, treatment will be staggered so that each subsequent subject cannot be infused with Cytosan until at least 2 weeks after the preceding subject. One day after receiving Cytosan, subjects will be infused with SB-728-T (5 to 30 billion cells). Six weeks after SB-728-T infusion, subjects with CD4 cell counts >500 cells/mm³ will undergo a 16 week TI during which time their anti-retroviral therapy will be discontinued. HAART will be reinstated in subjects whose CD4 T-cell counts drop to <500 cells/mm³ and/or whose HIV-RNA increases to >100,000 copies/mL for three consecutive weekly measurements. At the end of the TI, subjects with a sustained detectable viral load or CD4 T-cell count <500 cells/mm³ will be reinstated on HAART. Subjects with an undetectable viral load will remain off HAART until HIV RNA levels are detectable or their CD4 T-cell count drops below 500 cells/mm³ for three consecutive weekly measurements.

About Sangamo's HIV Pipeline of Programs

As part of a collaboration with scientists at City of Hope and the University of Southern California, under a \$14.5 million CIRM Disease Team Research Award, Sangamo is also developing an approach to modify a patient's own HSCs to circumvent the need to find matched donors that carry the delta-32 CCR5 mutation while providing a renewable and long-lasting source of HIV-resistant cells. Specifically, the grant funds the development up to submission of a an Investigational New Drug (IND) Application of a ZFN approach to treat AIDS patients by first isolating their HSC, modifying them using CCR5-specific ZFNs, and then re-infusing them to reconstitute the immune system with CCR5-negative, HIV-resistant immune cells.

About HIV/AIDS

HIV stands for Human Immunodeficiency Virus. HIV infection kills or impairs cells of the immune system progressively destroying the body's ability to fight infections and certain cancers resulting in AIDS (Acquired Immune Deficiency Syndrome). Individuals diagnosed with AIDS are susceptible to opportunistic infections, infections that usually are not as frequent or severe in healthy individuals. At the end of 2008, an estimated 1,178,000 persons aged 13 and older were living with HIV infection in the United States. Of those, 20% had undiagnosed HIV infections. In 2009, the estimated number of persons diagnosed with AIDS in the United States was 35,000. According to UNAIDS/WHO, over 2.6 million people were infected with HIV in 2009. There are now over 33 million people living with HIV and AIDS worldwide.

About Sangamo

Sangamo BioSciences, Inc. is focused on research and development of novel DNA-binding proteins for therapeutic gene regulation and genome editing. Sangamo has a Phase 2 clinical trial and two Phase 1 / 2 clinical trials to evaluate the safety and efficacy of a novel ZFP Therapeutic® for the

treatment of HIV/AIDS. Other therapeutic programs are focused on monogenic diseases, including hemophilia and hemoglobinopathies. Sangamo's core competencies enable the engineering of a class of DNA-binding proteins known as zinc finger DNA-binding proteins (ZFPs). By engineering ZFPs that recognize a specific DNA sequence Sangamo has created ZFP transcription factors (ZFP TFs) that can control gene expression and, consequently, cell function. Sangamo is also developing sequence-specific ZFP Nucleases (ZFNs) for gene modification. Sangamo has established strategic partnerships with companies in non-therapeutic applications of its technology including Dow AgroSciences and Sigma-Aldrich Corporation. For more information about Sangamo, visit the company's website at www.sangamo.com.

ZFP Therapeutic® is a registered trademark of Sangamo BioSciences, Inc.

This press release may contain forward-looking statements based on Sangamo's current expectations. These forward-looking statements include, without limitation, references to clinical trials of ZFP Therapeutics in HIV/AIDS, the timing and availability of clinical data, the research and development of novel ZFP TFs and ZFNs as ZFP Therapeutics, applications of Sangamo's ZFP Therapeutics to treat specific human disease as well as establishing strategic partnerships for therapeutic programs and references to anticipated cash and investment balance. Actual results may differ materially from these forward-looking statements due to a number of factors, including technological challenges, uncertainties relating to the initiation, completion and outcome of stages of ZFP Therapeutic clinical trials, Sangamo's ability to develop commercially viable products and technological developments by our competitors. See Sangamo's SEC filings, and in particular, the risk factors described in Sangamo's Annual Report on Form 10-K and most recent Quarterly Reports on its Form 10-Q. Sangamo BioSciences, Inc. assumes no obligation to update the forward-looking information contained in this press release.

The Wall Street Journal
January 10, 2012

Merck Will Consider Deals To Expand Hepatitis C Drug Lineup

By Peter Loftus

(San Francisco) –Merck & Co. (MRK) will consider making acquisitions as part of its strategy to develop the next generation of hepatitis C treatments, the drug maker's research chief said Tuesday.

The search for better hepatitis C drugs has produced some eye-popping deals in the drug industry recently, including Gilead Sciences Inc. (GILD) planned \$11 billion purchase of Pharmasset Inc. (VRUS) and Bristol-Myers Squibb Co.'s (BMY) agreement to acquire Inhibitex Inc. (INHX) for \$2.5 billion.

Merck last year began selling a new hepatitis C drug, Victrelis. But Merck and its rivals are developing newer regimens they hope will be more effective and part of all-oral regimens, eliminating an injectable drug that is part of the current standard of care.

Peter Kim, president of Merck's research division, told investors at the J.P. Morgan health-care conference here Tuesday that an experimental hepatitis C drug, MK-5172, will be the "cornerstone" of an eventual all-oral therapy for hepatitis C. It is currently in mid-stage testing.

He said Merck could take any of three approaches to pursue an all-oral regimen. It may pursue combining MK-5172 with other experimental drugs in earlier stages of testing at Merck whose mechanisms of action Merck hasn't yet disclosed.

Or, it could collaborate with other companies by combining MK-5172 with other drugs in development, including a "potential acquisition of assets that might be out there." If it's not possible to collaborate, Merck would study MK-5172 in combination with other new drugs when they reach the market, Kim said.

Asked if Merck would pursue a so-called "nucleotide"--the class of drugs developed by Pharmasset and Inhibitex--Kim said Merck was "looking into that," and will address that topic at a future date.

While Merck considers expanding its hepatitis C portfolio, rival Vertex Pharmaceuticals Inc. (VRTX), which sells the new treatment Incivek, is content with its stable of experimental hepatitis C treatments.

Jeffrey Leiden, who will become Vertex's chief executive next month, said in an interview "we have our pipeline, and we're very happy with it." Vertex is in mid-stage testing of VX-222 and last year licensed two nucleotides in early stages of testing.

Separately, Merck Chief Executive Kenneth Frazier said the company had resumed standard shipping for shingles vaccine Zostavax. Production problems in recent years have resulted in shipping delays to customers.

Annual Bleeding Events And Frequency Of Infusions Reduced By Preventive Hemophilia A Treatment

A Rush University Medical Center led international research team has announced that a treatment to prevent bleeding episodes in children with hemophilia A also is effective for adolescents and adults.

The preventive therapy will "optimize care for hemophilia patients of all ages by stopping unexpected bleeding events that can have a detrimental impact on the lives of patients," said Dr. Leonard Valentino, director of the Rush Hemophilia and Thrombophilia Center and principal investigator on the study. The study results appeared in the January online version of the Journal of Thrombosis and Haemostasis. Valentino is associate professor of Pediatrics at Rush University's Rush Medical College.

The study, sponsored by Baxter Healthcare Corporation, was conducted as part of a comprehensive clinical study of ADVATE Antihemophilic Factor (Recombinant), Plasma/Albumin Free Method (rAHF-PFM) to compare the effectiveness of two prophylactic treatment regimens, as well as between on-demand and prophylaxis treatments, in preventing bleeding in previously treated patients with severe or moderately severe hemophilia A. It is the first study designed to generate prospective data for stringent comparisons of bleeding rates.

Hemophilia A is a rare, inherited, potentially deadly blood clotting disorder that affects 400,000 people worldwide, most of them males. Approximately one in 5,000 individuals is born with hemophilia annually.

In people with hemophilia A, a protein called clotting factor VIII is either absent or present at low levels. Factor VIII replacement, such as rAHF-PFM, is considered the treatment of choice for managing hemophilia A patients who lack inhibitors (antibodies) of factor VIII.

About 90 percent of people who have hemophilia have type A. Of these, 70 percent have the severe form of the disorder, indicated by a factor VIII level of less than 1 percent of normal.

Patients with severe disease are at particular risk for spontaneous bleeding into joints, muscles and internal organs, as well as trauma-induced bleeding following injury and surgery. Joint bleeding may occur as frequently as 20 to 30 times a year, resulting in clinically significant hemophilia-related arthritis.

"The main goal of replacement therapy is to prevent this pathology," Valentino said.

Primary prophylaxis is already the standard of care for children with hemophilia A. It is believed that the early initiation of prophylaxis may confer a protective effect against factor VIII inhibitor, the most serious complication associated with replacement therapy.

Adult hemophilia patients are treated either in response to bleeding (on demand) or with regular infusion of clotting factor to prevent bleeding and further joint damage. However, while on-demand

treatment can slow the progression of hemophilia-related arthritis, it does not seem to prevent the condition.

In the Rush study, one regimen was based on common practice with every-other-day dosing. The other was customized for each individual based on the drug's activity in the body (pharmacokinetics, or PK) with every-third-day dosing. PK-tailored prophylaxis offers an alternative to standard prophylaxis for the prevention of bleeding.

Study participants aged 7 to 65 years received six months of on-demand treatment with dosing dependent on the severity and type of bleeding episode. After completing the on-demand treatment period, subjects were randomized to receive 12 months of either standard or PK-tailored prophylaxis treatment. Once the prophylaxis period began, factor VIII levels were assessed every three months.

Of the 66 subjects in the study, 22 (33.3 percent) who received prophylaxis had no bleeding episodes, in contrast to the patients treated on demand. No subject developed factor VIII inhibitors. The patients who achieved these results were adherent to the prescribed number of prophylactic infusions.

Compared with on-demand treatment, both prophylaxis regimens significantly reduced bleeding, including spontaneous and traumatic hemorrhaging, and improved the quality of life for adolescent and adults patients. Results of the study suggest that prophylaxis is the optimal treatment for patients with severe hemophilia. Data from the study also confirm and extend the safety and effectiveness of rAHF-PFM for controlling and preventing bleeding in the management of hemophilia A.

The study findings suggest that the PK-tailored prophylaxis regimen, which used similar amounts of rAHF-PFM and one fewer infusion per week, is a viable treatment alternative to standard prophylaxis. The availability of this option could increase treatment adherence, particularly in children and adolescents, for whom compliance with long-term medical regimens is especially challenging. Additionally, the study confirms and extends the safety and effectiveness of rAHF-PFM for controlling and preventing bleeding in the management of hemophilia A.

The National Institutes of Health
January 11th, 2012

Vitamin D may improve bone health in those taking anti-HIV drug
NIH study suggests benefits for young people on long-term tenofovir treatment

Vitamin D may help prevent hormonal changes that can lead to bone loss among those being treated for HIV with the drug tenofovir, according to the results of a National Institutes of Health network study of adolescents with HIV.

Tenofovir is widely used to treat HIV infection. However, the drug causes symptoms that resemble those of vitamin D deficiency, causing bones to lose calcium and reducing bone density. The study found that large monthly doses of vitamin D reduced blood levels of a hormone that stimulates calcium release from bones.

"What we've found suggests vitamin D could be used to counteract one of the major concerns about using tenofovir to treat HIV," said Rohan Hazra, M.D., of the Pediatric, Adolescent and Maternal AIDS Branch of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the NIH institute that funds the networks. "People in their teens and twenties may be on anti-HIV treatment for decades to come, so finding a safe and inexpensive way to protect their long-term bone health would be a major advance."

The findings were published online in *Clinical Infectious Diseases*.

Vitamin D helps the body absorb calcium to build bones. When the body is deficient in vitamin D, levels of a hormone called parathyroid hormone rise. This rise triggers activity that draws calcium from bones. As a result, the bones become more fragile and can break more easily. Parathyroid hormone also tends to be elevated in people taking tenofovir, whether or not they have sufficient vitamin D.

Because parathyroid hormone levels are elevated in people taking tenofovir in much the same way as they are in people with vitamin D deficiency, the researchers theorized that vitamin D might counteract the bone-depleting effects of tenofovir.

The study was conducted by first author Peter L. Havens, M.D., of the Medical College of Wisconsin and Children's Hospital of Wisconsin, Milwaukee; Dr. Hazra; Kathleen Mulligan, Ph.D., of the University of California at San Francisco; and other researchers affiliated with the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) and the International Maternal–Pediatric–Adolescent AIDS Clinical Trials (IMPAACT) Group.

In addition to funding from NICHD, funding was also provided by the National Center for Research Resources, the National Institute on Drug Abuse, and the National Institute of Mental Health. About 200 18- to 25-year-olds on antiretroviral therapy took part in the study. Study participants included young adults taking tenofovir and those receiving other forms of anti-HIV treatment. Each month, the adolescents and young adults in the study took a 50,000-unit dose of vitamin D or placebo. At the end of the three months, parathyroid hormone levels had fallen about 14 percent among participants taking tenofovir and vitamin D but remained unchanged in participants taking

other kinds of anti-HIV medication. However, youth taking tenofovir still had higher parathyroid hormone levels than those on other anti-HIV drugs. The researchers don't know if longer treatment with vitamin D would further reduce parathyroid hormone levels.

The recommended daily dose of vitamin D is 600 units. The authors noted that they observed no adverse effects from the vitamin D treatment during the 3 months of this study.

The researchers are now making plans for a two-year follow-up study to examine the longer-term safety of vitamin D in a similar group of HIV-infected youth taking antiretroviral regimens containing tenofovir, and to determine if the changes in parathyroid hormone result in improvements in bone density.

Provided by National Institutes of Health

Essential Health Benefits: HHS Informational Bulletin

On December 16, 2011, the Department of Health and Human Services issued a bulletin outlining proposed policies that will give states more flexibility and freedom to implement the Affordable Care Act. This bulletin describes a comprehensive, affordable and flexible proposal and informs the public about the approach that HHS intends to pursue in rulemaking to define essential health benefits.

HHS is releasing this intended approach to give consumers, states, employers and issuers timely information as they work towards establishing Affordable Insurance Exchanges and making decisions for 2014. This approach was developed with significant input from the American people, as well as reports from the Department of Labor, the Institute of Medicine, and research conducted by HHS.

Essential Health Benefits

The Affordable Care Act ensures Americans have access to quality, affordable health insurance. To achieve this goal, the law ensures health plans offered in the individual and small group markets, both inside and outside of the Affordable Insurance Exchanges (Exchanges), offer a comprehensive package of items and services, known as “essential health benefits.” Essential health benefits must include items and services within at least the following 10 categories:

1. Ambulatory patient services
2. Emergency services
3. Hospitalization
4. Maternity and newborn care
5. Mental health and substance use disorder services, including behavioral health treatment
6. Prescription drugs
7. Rehabilitative and habilitative services and devices
8. Laboratory services
9. Preventive and wellness services and chronic disease management, and
10. Pediatric services, including oral and vision care

Intended Approach: Comprehensive and Flexible

HHS intends to propose that essential health benefits are defined using a benchmark approach. Under the department’s intended approach announced today, states would have the flexibility to select a benchmark plan that reflects the scope of services offered by a “typical employer plan.” This approach would give states the flexibility to select a plan that would best meet the needs of their citizens.

States would choose one of the following benchmark health insurance plans:

- One of the three largest small group plans in the state by enrollment;
- One of the three largest state employee health plans by enrollment;
- One of the three largest federal employee health plan options by enrollment;

- The largest HMO plan offered in the state’s commercial market by enrollment.

If states choose not to select a benchmark, HHS intends to propose that the default benchmark will be the small group plan with the largest enrollment in the state.

The benefits and services included in the benchmark health insurance plan selected by the state would be the essential health benefits package. Plans could modify coverage within a benefit category so long as they do not reduce the value of coverage.

To prevent federal dollars going to state benefit mandates, the health reform law requires states to defray the cost of benefits required by state law in excess of essential health benefits for individuals enrolled in any plan offered through an Exchange. However, as a transition in 2014 and 2015, some of the benchmark options will include health plans in the state’s small group market and state employee health benefit plans.

These benchmarks are generally regulated by the state and would be subject to state mandates applicable to the small group market. Thus, those mandates would be included in the state essential health benefits package if the state elected one of the three largest small group plans in that state as its benchmark.

This approach would provide maximum flexibility to states, employers and issuers while providing quality, comprehensive, coverage for consumers.

Coverage

Essential health benefits must include coverage of services and items in all 10 statutory categories. Based on our research, we believe that these benchmarks will cover most of the essential health benefits outlined by the Affordable Care Act. These categories include preventive care, emergency services, maternity care, hospital and physician services, and prescription drugs. If a state selects a benchmark plan that does not cover all 10 categories of care, the state will have the option to examine other insurance plans, including the Federal Employee Health Benefits Plan, to determine the type of benefits that must be included in the essential health benefits package.

Allowing Plans Flexibility to Innovate and Consumers Greater Choice

To meet the EHB coverage standard, HHS intends to require that a health plan offer benefits that are “substantially equal” to the benchmark plan selected by the state and modified as necessary to reflect the 10 coverage categories. Health plans also would have flexibility to adjust benefits, including both the specific services covered and any quantitative limits, provided they continue to offer coverage for all 10 statutory EHB categories and the coverage has the same value. Permitting flexibility will provide greater choice to consumers, promoting plan innovation through coverage and design options, while ensuring that plans providing EHBs offer a certain level of benefits.

Updating the Approach

The department intends to propose that benchmarks will be updated in the future, and that state mandates outside the definition of essential health benefits may not be included in future years. The

Bulletin also notes that updating the benchmark will allow benefits to reflect the most up-to-date medical and market practices.

How We Got Here: The Process

While the law calls on the department to provide details regarding essential health benefits, this has been a team effort.

As required by the Affordable Care Act, in April, the Department of Labor provided a report to HHS on employer-sponsored health insurance coverage. This report detailed the benefits typically covered by employers detailed the benefits typically covered by employers. At the request of HHS, the Institute of Medicine provided its recommendations on a process for defining and updating the benefits that should be included in the essential health benefits package.

HHS also conducted a series of listening sessions to collect public comment and hear directly from the American people, doctors, nurses, Members of Congress and all interested stakeholders.

It is important to note that the Affordable Care Act distinguishes between a health plan's covered services, and the plan's cost-sharing features, such as deductibles, copayments, and coinsurance. The cost-sharing features will be addressed in separate rules and will determine the actuarial value of the plan, expressed as a "metal level" as specified in statute: bronze at 60% actuarial value, silver at 70% actuarial value, gold at 80% actuarial value, and platinum at 90% actuarial value.

Although this paper represents only the intended regulatory approach, public input on this paper is encouraged—comments can be sent on essential health benefits, are due by January 31, 2012, and can be sent to: EssentialHealthBenefits@cms.hhs.gov.

The Catch: The Uninsurables

By Allison Bell

About 129 million non-elderly U.S. residents have health conditions that could make it difficult for them to buy health coverage in a state that allows medical underwriting, according to analysts at the office of the Assistant Secretary for Planning and Evaluation (ASPE) at the U.S. Department of Health and Human Services (HHS).

The analysts discuss pre-existing condition rates in a commentary supporting the Patient Protection and Affordable Care Act of 2010 (PPACA).

If PPACA takes effect as written and works as drafters expect, it will ban most types of medical underwriting starting in 2014. Carriers would still be able to charge higher rates for older insureds and insureds who smoke, and, in some cases, they might be able to use rate surcharges and discounts as wellness program incentives.

The ASPE analysts came up with two estimates of the size of the potentially uninsurable population.

One includes individuals who have such serious health problems, such as cancer or hemophilia, that they qualify for the new federal Pre-existing Condition Insurance Plan risk pool program.

The analysts also prepared a second estimate that includes people with conditions such as obesity, asthma and hypertension who may be able to get coverage but, in markets where individual insurers apply strict underwriting rules, may face the prospect of dealing with higher rates and pre-existing condition exclusions.

About 50 million U.S. residents, or 19% of non-elderly U.S. residents, have serious enough health problems to be uninsurable according to the PCIP standards, the analysts say.

When conditions such as obesity are included, about 50% could be considered uninsurable, the analysts say.

Today, the analysts say, many of those individuals do have health coverage, either because they are in government-run health plan programs or because they are in employer-sponsored group health plans and face no medical underwriting process.

About 82 million group plan members have pre-existing conditions that could make them uninsurable or difficult to insure if they applied for individual coverage and faced an individual underwriting process, the analysts report.

In the 55-to-64 age group, 48% to 86% of the individuals could be considered uninsurable or difficult to insure, the analysts estimate.

DOUBLE TROUBLE

Joyce Martin and other researchers at the National Center for Health Statistics (NCHS) have confirmed that the ratio of twin births to all births has increased rapidly in the United States since 1980.

In 2009, 1 of every 30 babies born in the United States was a twin, up from 1 in 53 babies born in the United States in 1980, the researchers report in a twin birth rate brief released by the federal Centers for Disease Control and Prevention (CDC). From 1915 to 1980, the ratio held steady at about 1 twin to 30 singletons.

The vast majority of the twins were healthy, but women who are carrying twins are more likely to develop a form of high blood pressure that can lead to strokes, they are more likely to need bed rest, and they are more likely to give birth prematurely. Pregnancies involving triplets, quadruplets and other "super twins" are even more likely to lead to serious complications.

Older women tend to have more twins than younger women, even when no fertility treatments are involved, but the NCHS researchers say the increase in maternal ages in recent years appears to explain only about one-third of the increase in the twin birth rate.

The states that require state-regulated insurers to cover at least one round of in vitro fertilization for couples with fertility problems are Arkansas, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, New Jersey and Rhode Island, according J. Ryan Martin and other researchers at the Yale University medical school.

The states with the biggest increases in twin birth rates between 1980 and 2009 are Connecticut, Hawaii, Massachusetts, New Jersey and Rhode Island, according to the NCHS researchers.

EMPTY MAILBOX SYNDROME

Life, health and property-casualty insurers sent 11% less direct mail to U.S. consumers during the third quarter of 2011 than during the comparable period in 2010, according to direct mail analysts at Mintel Comperemedia, Chicago.

Direct mail volume fell 17% for life insurers, 8% for p-c insurers, and 7% for health insurers, the analysts estimate.

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State boards, commissions could be cut, combined

By Philip Walzer

How many potato boards does one commonwealth need?

Not two, according to Gov. Bob McDonnell.

McDonnell has proposed doing away with about 30 state boards or commissions by eliminating them or merging them into other governing and advisory bodies. The General Assembly, which will reconvene Wednesday, must approve the changes.

The Virginia Seed Potato Board, which meets annually and establishes regulations for seed potatoes, those potatoes used to cultivate a crop, would be merged into the Potato Board. Similarly, the Bright Flue-Cured and Dark-Fired tobacco boards would be fused into one tobacco board.

"We can still accomplish what needs to be accomplished," said the state's agriculture commissioner, Matthew Lohr, "and be more efficient in the process."

Among other potential victims: the Interagency Dispute Resolution Council, the Hemophilia Advisory Board, and the Advisory Council to the Southeastern Interstate Forest Fire Protection Compact.

"Each one of these boards may not be a huge hit on the budget," said Jeff Palmore, director of policy development and deputy counselor to McDonnell. "But each one of them may have reimbursements to members for travel. Each one of them requires staff time to manage. The attorney general's office has to provide legal advice to each one of them.

"Combined," Palmore said, "their impact does have a big effect on the operations of state government."

The other pieces of McDonnell's reorganization plan include eliminating nine state agencies, moving four state offices and deregulating three occupations. Together with the reduction in boards, they would save the state more than \$2 million a year, Palmore said.

Some worry the proposals could go beyond bureaucratic streamlining to sway state policies.

The Virginia Public Broadcasting Board is among the boards that McDonnell wants to drop. Its functions would be transferred to the Virginia Board of Education. McDonnell "feels this is a more efficient way to organize the system rather than have a standalone organization," said Palmore, who noted that the broadcasting board hadn't met for two years.

But Bert Schmidt, the CEO of WHRO, the local public broadcasting network, said the proposal bolsters McDonnell's attempts to kill state aid for public broadcasting. "His intent from day one was

to defund us," Schmidt said.

Earlier this year, McDonnell cut state funding for WHRO by \$370,000 a year. The governor's budget proposal for next year would eliminate state funding for public broadcasting, costing the local network an additional \$640,000 a year.

The broadcasting board "allows for a real partnership, which we've made for many, many years with Democratic and Republican governors until this one," Schmidt said. McDonnell has rebuffed Schmidt's invitations to meet and "chosen not to use this board at all," he said.

Toni Cacace-Beshears, CEO of Children's Harbor, a nonprofit that provides child care and education across the region, sees potential for good and harm if the Child Day Care Council is abolished.

The council, which sets standards for day care centers, has grown from 13 members to 29, according to a November report from the Governor's Commission on Government Reform and Restructuring, which recommended the board purges. Its work would be transferred to the state Board of Social Services. That board, which has nine members, would add two to represent day care centers.

Cacace-Beshears acknowledged that the council has gotten "dragged down because it is a bigger group." But under the proposed setup, "what would worry me is if people who didn't have the best interests of children at heart" influenced child care decisions.

Among the business-related casualties would be the Small Business Advisory Board. The reform panel's report noted the board's chronic absentee problem: It hasn't mustered a quorum in the past eight meetings. It also duplicates the efforts of the state's Small Business Commission, Palmore said.

"Obviously, helping small businesses to succeed and grow is an important goal that Gov. McDonnell embraces," he said. "But it's hard to argue that you need two separate boards."

The commission's report offered other examples of bureaucratic redundancy: It saw no need for the Northern Virginia Transportation Commission since Virginia also has the Northern Virginia Transportation Authority.

And some boards on the hit list had even more severe attendance issues than the small business board. The Public Buildings Board has met four times in the last seven years.

The Boating Advisory Committee is still on the books, but "there are no current appointees," the commission's report said. The panel hasn't met since Gov. L. Douglas Wilder's tenure, it said. Wilder left state office in 1994.

This isn't the first time McDonnell has taken a swipe at the boards, which number more than 300. Last year, the General Assembly agreed to do away with nine, Palmore said. They included the Medal of Valor Review Board, the Plant Pollination Advisory Board, and the Migrant and Seasonal Farmworkers Board.

High-risk insurance pool out of funds

By Mike Dennison

Montana's federally funded health insurance "high risk pool" for the hard-to-insure will blow through its initially allocated \$16 million this year, and needs another \$6 million to \$7 million to cover its 2012 costs, officials said Tuesday.

The \$16 million, issued in mid-2010 as part of the federal health care-reform law, was supposed to cover costs of the subsidized health insurance program through 2013, for as many as 400 people covered by the pool.

Yet initial cost estimates turned out to be too low, because the medical costs per covered customer are higher than expected, said Cecil Bykerk, executive director of Montana's pool.

"Our numbers (for enrollment) were fairly accurate, but per-member, per-month claim costs have been much higher than the original assumptions that we used," he said.

Bykerk said the U.S. Health and Human Services Department (HHS) has committed to funding Montana's program through 2012 and will need to provide more money to cover program costs for 2013 and partly into 2014.

Montana's pool currently provides health insurance for about 290 people, who are eligible if they've been without insurance for at least six months and have a pre-existing condition that made them uninsurable or made available insurance unaffordable.

Bykerk said people getting coverage through the pool typically have high-risk conditions or diseases, such as cancer, diabetes, heart conditions, HIV-positive, hemophilia or organ transplants.

The pool offers insurance at a price that would be charged the customers if they were healthy. It then covers the medical costs, which far exceed the income from premiums paid by the customers.

The pools, set up in every state in 2010, are part of the controversial health-reform law known to detractors as "Obamacare."

They're designed to offer affordable coverage to hard-to-insure people until 2014, when new, federal subsidies kick in to help people buy health insurance they're required to have.

Bykerk said Montana officials used a formula, based on enrollment and projected costs, to determine the program's estimated cost, and were allocated \$16 million in federal funds in mid-2010 to fund the program through 2013.

Montana state insurance officials estimated that 400 people would enroll, and proposed capping the program when it reached that number.

The program has never hit the 400 enrollees, but the cost per enrollee has been much higher than anticipated, he said.

Last summer, states running their own program submitted projections to HHS. Reports from nine states, including Montana, showed that they were exceeding their initial allocation of money.

Montana spent about \$8.5 million of its funds through 2011, but will need an additional \$6 million to \$7 million, on top of its initial \$16 million, just to get through 2012, state officials said. The program will do another projection in mid-2012, to determine what additional funds it will need to cover costs for 2013, Bykerk said.

Lucas Hamilton, spokesman for state Auditor Monica Lindeen, whose office oversees the pool, said it has served more than the 290 people currently covered.

Some have qualified for the subsidized coverage, bought it, used its benefits, and then stopped paying for the coverage.

Hamilton said there obviously was a “pent-up need” for the program when it began, and that Lindeen’s office is still promoting it.

“There was a serious need for health coverage, and this fit the bill,” he said.

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Judge in Alabama Medicaid fraud case declares seized computer records are authentic

By Brendan Kirby, Press-Register

MOBILE, Alabama — With a month long Medicaid fraud trial looming, federal prosecutors in here this week won an important evidentiary victory.

U.S. District Judge Kristi DuBose ruled that disputed computer records seized from a Birmingham pharmacy are authentic, but said she would wait until trial before deciding whether to admit them into evidence.

Defense lawyers objected to records taken from the computers of MedfusionRX in 2009 on grounds that the FBI agents failed to take steps to ensure that they properly preserved data copied during the raid.

After hearing from an expert witness called by the prosecution, DuBose determined that prosecutors had met their burden in proving that the documents and spreadsheets are accurate copies of information that was on the computers.

Eight defendants, including the owners of Medfusion, stand accused of a conspiracy to defraud the Alabama Medicaid Agency and private insurance companies by inflating the amount of specialty drugs ordered for patients with hemophilia and other blood diseases.

Lawyers for defendants Jeff Vernon and Chris Vernon argued that investigators failed to properly authenticate the copies that they made.

Gus Dimitrelos, a computer forensic examiner who has a \$16,000 annual contract with the U.S. Attorney's Office but was not involved in this investigation, testified that he reviewed the FBI's techniques and the data it examined.

"All forensically sound, all proper techniques," he pronounced.

Dimitrelos testified that there was no damage to any of the documents recovered by the FBI.

"I was able to look, and there was nothing," he said. "They are pristine and forensically sound copies."

Prosecutors allege that Medfusion and another special pharmacy in Loxley, Hemophilia Infusion Managers, paid kickbacks to the owner of a company formed to help patients order expensive protein replacement medicine called Factor.

One of the Loxley pharmacy's owners, Anthony Eric Mosley, said in an interview last year that he paid money for referrals but said that attorneys advised him the payments were legal commissions.

Medicaid: a year of excruciating decisions

By Christine Vestal

In health care history, 2012 will be remembered for the U.S. Supreme Court's upcoming decision on the Obama administration's health overhaul. But in the states, 2012 will likely be remembered less as an historic turning point than as a gradual continuation of their longstanding struggles to get Medicaid costs under control.

That's not to say the states aren't watching the Supreme Court closely. The case set to be heard in March and decided in June was brought by 26 states who argued the federal law's "individual mandate," as well as a massive expansion of Medicaid in 2014, were unconstitutional. While the outcome could have long-term consequences for states, it likely won't change their most pressing short-term budget considerations.

And those considerations are huge. Continuing sluggishness in the economy means that Medicaid rolls are still rising. But with the federal stimulus program over, support from Washington is no longer going up along with enrollments. The result is that Medicaid spending is ballooning, despite deep cuts states have made over the past three years to make the federal-state health insurance program for the poor less and less generous.

Two years ago, Medicaid eclipsed K-12 education as the most expensive item in state budgets. Since then, it has only kept growing. Medicaid now comprises 24 percent of state budgets, when federal funds are counted. That's up from 22 percent last year, according to the National Association of State Budget Officers. The upward spiral seems to be continuing. Even as states get ready to write their budgets for fiscal year 2013, which starts in July in most states, half of them expect to be wrestling with Medicaid shortfalls in their 2012 budgets, according to a survey by the Kaiser Family Foundation.

Making the job for fiscal 2013 even more difficult for states are new federal restrictions and an increasing number of court rulings that limit states' options for trimming their programs. Recent cuts have run so deep that they are pushing the limits of what health care providers and patient advocates will tolerate without seeking court review. That's especially true in Western states, where the 9th U.S. Circuit Court of Appeals has been halting Medicaid cuts and ordering states to spend a year or more to study the issue and hold public hearings.

Other restrictions on states come from the Affordable Care Act, which prevents states from doing anything that would lower enrollment. In addition, a new federal rule proposed late last year would require states to produce data showing that cuts to hospital and doctor fees won't make it harder for Medicaid patients to get the care they need.

One state's woes This wall of restrictions is all too familiar in Washington State, where lawmakers are grappling with painful cuts aimed at closing a \$2 billion budget gap. In a special budget session last November, Democratic Governor Christine Gregoire proposed a list of

controversial Medicaid cuts, including terminating what is known as a “lifeline” medical program for some 22,000 disabled adults. She also proposed limiting the use of brand-name prescription drugs; eliminating coverage for over-the-counter drugs and adult dental services; slashing payments to small hospitals that treat a large percentage of uninsured patients; and defunding language interpreters who serve 70,000 non-English speaking beneficiaries.

Perhaps most painful is her proposal to terminate a 25-year-old state-funded “basic health plan” for 35,000 low-income adults who are not poor enough to qualify for Medicaid. Ironically, the Affordable Care Act encourages other states to develop plans like the one Gregoire would end. In fact, the federal government said it would pay for half of Washington State’s ongoing costs for the model program. But Gregoire is asking lawmakers to terminate the program altogether because she says the state cannot afford to pay even half of the costs.

None of Gregoire’s proposed Medicaid cuts were approved in the special session. So lawmakers, who convened their regular 2012 session this week, are taking a fresh look at the proposals.

What won’t be on the legislative agenda is what Washington State isn’t allowed to do. A union-led ballot measure last year forced the state to reinstate a \$32 million training program for home health care workers that the legislature had eliminated. And a three-visit limit on non-emergency use of emergency rooms, designed to save \$70 million, was lifted after a superior court judge issued an injunction order. The governor’s proposal to limit Medicaid coverage of certain prescription drugs may also be taken off the agenda, if federal objections cannot be satisfied.

No more federal help The fundamental problem all states face is that while Medicaid rolls continue to grow, federal support for the jointly-funded program is not keeping pace — and neither is state revenue. More than \$100 billion in extra federal support under the 2009 stimulus program ran out last July. As a result, state Medicaid spending jumped 29 percent between budget years 2011 and 2012 to make up for the loss of federal funds.

This year, even with program reductions, most states will find it difficult to come in under that higher spending level. Meanwhile, additional federal help is not an option. Although Congress exempted Medicaid from across-the-board cuts in its federal deficit-reduction deal last year, no one expects Washington to ship additional federal dollars to the states for Medicaid. That means the extra burden is all on states’ shoulders, according to Alan Weil, director of the National Academy of State Health Policy. “State revenues are growing,” Weil says, “but Medicaid is going to eat that up and more in many states.”

In addition, states are barred from doing anything that would lower Medicaid enrollment below the income levels called for in the national health law’s 2014 Medicaid expansion. That includes raising premiums and co-pays to levels the federal government considers unaffordable for low-income patients.

That leaves states with relatively few options when it comes to controlling Medicaid costs. They can reduce provider fees and eliminate optional benefits. States can also expand Medicaid managed care programs and experiment with broad changes in the way health care is delivered. These labor-intensive system-wide changes have twin goals of improving care and reducing costs through better coordination. But in most cases, any savings they generate are not expected to make a serious dent

in state budgets in the short term.

Making matters worse, federal regulatory processes continue to drag on, says Dan Crippen, executive director of the National Governors Association. States are not allowed to experiment with their Medicaid programs without receiving waivers from the federal government, but the feds have been slow to issue decisions. “As we approach the beginning of legislative sessions in many states,” Crippen says, “governors are faced with making tough decisions without adequate information about programs and their funding.”

Oregon is a case in point. Democratic Governor John Kitzhaber has had what he calls promising talks with the U.S. Department of Health and Human Services about a groundbreaking new health program the state is banking on to cut Medicaid spending this year.

By setting up so-called “coordinated care organizations” as the front door for patients, the state aims to abandon the impersonal and fragmented way most people receive health services today. In addition to improving health, the new system is expected to cut costs. But Kitzhaber worries that if federal approval doesn’t come early this year, those savings may not materialize.

Provider fees The 1965 federal Medicaid law only requires states to cover certain health care services. Those services include pregnancy and child birth-related services, pediatric care, hospitalization (except for mental illness), regular check-ups and long-term care for the elderly and disabled. Over the years, many states added optional services such as dental and vision, mental health, and a variety of others such as HIV therapies, hospice care, podiatry and occupational and speech therapy.

Since the Great Recession triggered a state fiscal crisis in 2009, many states have cut those optional benefits. Tennessee ended coverage of adult acne medicine. North Carolina stopped covering eye exams and glasses for adults. Massachusetts no longer covers dentures.

As a result, many states now have few places left to turn for savings but to cut the fees they pay doctors, hospitals and other health care providers in the coming budget year. At least 33 states cut provider fees in their 2012 budgets, according to a report by the National Association of Budget Officers; even more are expected to do so this year.

But states can cut hospital and doctor fees only so much without ending up in court — a trend that has accelerated in recent years as health care providers claim that state budget cuts are making it impossible to keep their doors open. Patients, too, say there aren’t enough doctors willing to take Medicaid to provide the care they need.

While the federal Medicaid statute requires states to set reimbursement rates “sufficient to enlist enough providers” so that health care for the poor is comparable to the care given to people with private health insurance, the law provides no standards for fee-setting. The federal government has so far left the calculation up to states.

A proposed federal rule published last April, however, would for the first time require states to show that lower rates will not make it harder for Medicaid patients to get doctor’s appointments. According to Matt Salo, executive director of the National Association of Medicaid Directors, the

new rule calls for extensive studies before a state can reduce provider fees — studies he says most Medicaid agencies lack the resources to carry out.

The issue will also come before the U.S. Supreme Court, in a case that has been overshadowed by the challenge to Obama's health care overhaul but may be just as important from the states' perspective. In a decision also expected this June, the high court will determine whether individuals can sue states for failure to comply with the federal Medicaid law if they cut provider fees too deeply. In recent years, successful lawsuits against state Medicaid programs have been most prevalent in states in the U.S. Court of Appeals for the Ninth Circuit: Alaska, Arizona, California, Hawaii, Idaho, Montana, Nevada, Oregon and Washington. But in the 45 years since the Medicaid law was enacted, legal experts say that nearly every state has had at least one Medicaid budget cut stopped because of successful lawsuits by patients, health care providers and other advocates.

Tough decisions As legislative sessions get started this year, a large number of states will have to address holes in their 2012 Medicaid budgets before taking on 2013 budgets.

California Governor Jerry Brown, a Democrat, tried to save \$145 million last year by eliminating an adult day care program that was generally agreed to have kept many seniors and people with disabilities out of costly nursing homes. In November, a successful lawsuit by advocates for the disabled forced the state to put back \$85 million for a scaled-down program. Those savings will have to be found elsewhere.

North Carolina Governor Bev Perdue, a Democrat, is battling Republican lawmakers over a nearly \$150 million projected shortfall in the state's Medicaid budget. Agency officials say that unless lawmakers come up with the needed funds, they will have to cut optional services such as hospice and mental health care, and possibly reduce fees to Medicaid doctors by as much as 20 percent.

In Maine, Republican Governor Paul LePage is proposing controversial cuts because the state already is spending \$220 million more than its two-year budget calls for. His solution: elimination of a program that serves 65,000 childless adults, including 19- and 20-year olds. He also wants to make it harder for parents to qualify for Medicaid and do away with adult dental coverage and other optional benefits.

But the governor is having a hard time selling his ideas even to fellow Republicans. If the GOP-controlled legislature approves the cuts, the governor's next battle will be with the federal government. Only a few states have been allowed to scale back the number of Medicaid beneficiaries, even when their programs are more expansive than the Medicaid law requires.

If the Affordable Care Act survives its high court test in June, the federal government plans to pay the full cost of Medicaid coverage for most of the low-income adults whom states are cutting from the rolls — but not until 2014. In the meantime, governors will have to make unpopular decisions that many of them will find extremely painful.

“Washington is a state with a political leadership whose instincts are exactly the opposite of what we've been forced to do,” says Gregoire's policy adviser, Jonathan Seib, noting that the governor supports Obama's health overhaul. “The goal is not to dismantle and contract, but to expand health care.”