

i n F O C U S

SPRING 2012



The Singular Importance of the Affordable Care Act

Dana Van Gorder, Executive Director
 dvangorder@projectinform.org

We devote a significant portion of this issue of *In Focus* to a discussion of the critical importance of and barriers to successful implementation of the Patient Protection & Affordable Care Act, signed into law by President Obama in 2010 to increase the number of Americans with health insurance and to bring needed reforms to our nation's health care system.

As we have written before, this is a moment of incredible opportunity to defeat both the HIV and hepatitis C epidemics—both of which Project

Inform is working to end. Research has proven that a person effectively treated for HIV can both increase his or her lifespan by decades, and reduce the chances that they might transmit HIV to others by as much as 96 percent. However, only half of 1.2 million HIV-positive Americans know their status or are linked to care and treatment. And shockingly, only one-fifth of people receiving HIV treatment have achieved undetectable levels of the virus—the true goal of antiretroviral treatment.

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Successful Implementation of the Affordable Care Act is Essential to Ending HIV/AIDS

Anne Donnelly, Director of Health Care Policy
 adonnelly@projectinform.org

March 23, 2012 marked the second anniversary of the Patient Protection and Affordable Care Act of 2010 (ACA). While far from perfect, the ACA represents a major victory for people with HIV. It makes significant strides toward correcting a health care system that has largely failed people with virtually all chronic medical conditions. Full implementation of the ACA is necessary to realize the goals of the National HIV/AIDS Strategy, particularly linking to and retaining more HIV-positive people in care and treatment, and reducing HIV related disparities.

In order to ensure access to the care and treatment necessary to improve health outcomes for HIV-positive individuals and dramatically reduce

new HIV infections, people with HIV need secure and affordable insurance coverage. The \$2 billion a year federal Ryan White Program has done an extraordinary job of filling gaps, however, need has dramatically increased while funding has remained flat, evidenced by ever increasing wait times for HIV care and treatment.

Additionally, it is clear that we can't defeat a major epidemic with a purely discretionary program that requires going back to Congress each year for increased funding.

Some important ACA provisions are already in place, but full coverage expansion occurs in 2014. In January of that year, many people with HIV will qualify for free medical care through

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The National HIV/AIDS Strategy, which Project Inform helped to establish and is helping to implement, is focused on making certain that significantly more people with HIV know their status, are linked to and retained in care and treatment. This effort, combined with other promising forms of prevention such as Pre-Exposure Prophylaxis or PrEP—which we also discuss on page 4—hold real potential for the nation to achieve the first AIDS-free generation.

2011 saw the introduction of powerful new medications that greatly increase one's ability to cure hepatitis C—although available treatments remain very difficult to tolerate. In coming years, newer medications will greatly simplify hepatitis C treatment. And so, it is also possible to imagine winning the battle against this epidemic within a decade. Again, however, far too few people at risk for hepatitis C have been tested (all baby-boomers should know their status), and there are many barriers to encouraging care and treatment for those who have been diagnosed hepatitis C-positive.

Ending the HIV and hepatitis C epidemics is entirely dependent upon the expansion of access to affordable health care provided under the Affordable Care Act. Significant portions of people living with and at risk for both diseases are currently uninsured or underinsured. While the nation's response to HIV has benefitted from the creation in 1990 of the Ryan White Program, which pays for care and treatment for many people with HIV who do not qualify for any form of

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an expansion of Medicaid, and others will receive federal subsidies to assist them to purchase an insurance plan offered through a Health Benefit Exchange (HBE), a new insurance market mandated by the ACA. Importantly, people with HIV will no longer have to become sick before qualifying for Medicaid—which is currently only available to adults who are medically disabled.

Both private insurance and the expanded Medicaid program will have to provide “Essential Health Benefits,” a new minimum standard for available coverage. Exchanges will be charged with making insurance options more understandable and making it easier to pick the right coverage. In addition, insurance companies will no longer be able to discriminate against people due to health status or gender, and there will be a cap on annual out-of-pocket spending.

Even as we recognize the second anniversary of passage of the ACA and implementation is moving forward, legal and political challenges threaten this important legislation. The Supreme Court is currently deliberating the validity of major pieces of the law, with a ruling expected in June. Although, many ACA supporters were discouraged by the tone of the Court's oral arguments, others have pointed to encouraging

public or private insurance, Congress is extremely unlikely to appropriate the funds necessary to assure services for all who need them. And no safety-net program whatsoever exists to pay for the care and treatment of people with hepatitis C who are unable to acquire some form of health care coverage.

Today, Project Inform is devoting considerable resources to the defense and successful implementation of the Affordable Care Act. We view opposition to this legislation as missing an essential truth. It is fiscally responsible to require all Americans to purchase health insurance, and even subsidize them to do so. Why? Because treating major illnesses like HIV and hepatitis C early costs far less than waiting until people are gravely ill and because, if people do become gravely ill and are uninsured, the cost of their care will ultimately fall to the taxpayer. Additionally, the ACA creates a significant opportunity to control healthcare costs.

I am enormously proud of the leadership of our two staff members who are working to assure the successful implementation of the Affordable Care Act, Anne Donnelly and Ryan Clary, both of whom have written articles for this newsletter. We encourage your questions about this pressing issue, and hope that we can turn to you in the event that it becomes necessary to mobilize people who care about ending HIV and hepatitis C to come to the defense of this just, humane and responsible legislation.

signs, including the line of questioning on Medicaid expansion which seemed to suggest it could be upheld. Experts have pointed out ways that health care reform provisions could move forward if only portions of the bill were upheld. In addition, some speculate that the significant investment in implementation at the federal and state level could allow some states to move forward even if the full bill is overturned by the Court. In addition to the legal challenges, Republican presidential candidates and many in Congress have vowed to repeal the ACA.

Project Inform and its partners, including HIV organizations and low-income health advocates, continue to respond at the Federal level to regulations issued by the Department of Health and Human Services (HHS), as well as attacks against health care reform and Medicaid, Medicare and Ryan White.

A new website, www.hivhealthreform.org, has been developed by Project Inform and its partners to provide the HIV community with the information needed to prepare for health care reform, take advantage of benefits already in place under the ACA, and take action to protect the ACA and the health care programs it builds upon.

At the same time we work to defend and implement health

successful implementation, continued on page 3



Affordable Care Act: An Unprecedented Opportunity to Fight Hepatitis C

Ryan Clary, Director of Public Policy
 rclary@projectinform.org

Relatively little is known about the health insurance status of people living with hepatitis C. This problem is complicated by the fact that an estimated 75 percent of the more than 4 million Americans carrying hepatitis C are unaware of their status, making it difficult to collect comprehensive data about this seriously under-addressed epidemic.

There is ample evidence, however, that a large percentage of hepatitis C-positive people are not insured, creating a major barrier to accessing new, lifesaving treatments and care. A study published last year in the journal *Hepatology* reviewed data from the National Health and Nutrition Examination Survey (NHANES), a large household survey overseen by the Centers for Disease Control and Prevention (CDC), and analyzed the health insurance status of hepatitis C-positive individuals who participated in the study. Most alarmingly, the study found that only 36 percent of people with hepatitis C who needed treatment had any form of insurance coverage.

These data suggest that the expansion of health care access that would result from the Affordable Care Act (ACA) is vital for people living with hepatitis C. Uninsured people with hepatitis C who do not qualify for Medicaid or Medicare currently do not have a safety net program like the Ryan White Program, which serves people with HIV, including those co-infected with hepatitis C. This leaves mono-infected people with few options to access the comprehensive care and treatment services needed to manage their health condition. In 2014, most will become insured through Medicaid expansion or by being able to purchase private insurance through their state's health insurance exchanges. ACA implementation should also provide an excellent opportunity to expand the number of people who are tested for hepatitis C, particularly if medical providers respond to the CDC's upcoming revised HCV screening guidelines, which will recommend that all baby boomers be tested for hepatitis C.

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care reform at the Federal level, California is moving forward quickly with ACA implementation, as well. A partial Medicaid expansion is already in place, workgroups are developing a full Medicaid expansion, and legislation that will help shape the Essential Benefits Package and other health care reform components is making its way through the State Legislature.

Health care reform holds great promise for people with HIV and for the effort to end the epidemic. It also presents some

Project Inform has prioritized advocacy on behalf of people living with and at risk for hepatitis C as the ACA is implemented. We have responded to draft regulations and fought for viral hepatitis screening, prevention, care, and treatment services to be included in the Essential Health Benefits (EHB) package that must be provided to newly insured individuals. We have also partnered with HIV advocates who are working to assure ACA implementation, resulting in a letter authored by Representative Barbara Lee (D-CA) and signed by over 50 of her Congressional colleagues urging Health and Human Services Secretary Kathleen Sebelius to ensure that people with HIV and viral hepatitis are guaranteed comprehensive health services.

Project Inform also helped establish Hepatitis Health Action, a national grassroots coalition of viral hepatitis advocates whose primary mission is defending the ACA from being repealed or defunded and who promote elements of the legislation that are of great value to fighting viral hepatitis. Project Inform and Hepatitis Health Action have focused efforts on the Prevention and Public Health Fund, which currently provides \$1 billion for health promotion, wellness, public health infrastructure, and prevention services. In the Fiscal Year 2012 appropriations bill, Congress approved \$10 million from the Fund for viral hepatitis prevention and testing services, a substantial investment in a challenging economic environment. Finally, through our management of the California Hepatitis Alliance (CalHEP), we are partnering with HIV and other chronic disease advocates to ensure that California is a leader in implementing health care reform in a way that ensures the protection of the state's vulnerable populations.

For more information about Project Inform's hepatitis C policy advocacy, contact Ryan Clary at rclary@projectinform.org.

very serious challenges. The overriding challenge is to ensure that gains made through health care reform are not lost to partisan politics. At stake is the health and well-being of millions of uninsured and underinsured Americans, including those living with HIV and other chronic conditions, who have been shut out of the health care system. Please join Project Inform and its partners in the effort to fully implement the spirit and law of the ACA by visiting www.hivhealthreform.org.



Major Progress is Made on an Important New HIV Prevention Option

David Evans, Director of Research Advocacy
 devans@projectinform.org

Pre-Exposure Prophylaxis, (PrEP) involves having HIV-negative people take the anti-HIV medication Truvada on a daily basis, along with continuing to use condoms, to prevent themselves from becoming infected with HIV. The strategy has shown such promise in clinical trials that Gilead Sciences, the maker of Truvada (tenofovir+FTC), is asking the U.S. Food and Drug Administration (FDA) to allow it to sell this medication for HIV prevention purposes and not solely as a treatment for HIV-positive people.

In a groundbreaking vote on May 10, an advisory committee to the FDA recommended that Truvada should be approved for prevention. The FDA itself seems to be poised to follow suit, but is under some pressure not to do so. Because we view PrEP as an essential addition to our arsenal of HIV prevention technologies, Project Inform asks that you weigh in on this important issue.

New data show that PrEP effectiveness can range from 90 to 99 percent when Truvada is taken every day as directed, and this was true in both men and women and for both anal and vaginal sex. Studies have also demonstrated, thus far, that the risk of side effects over a one- or two-year period are very low and that, aside from stomach upset and headache during the first couple of weeks of use, most people find Truvada very easy to tolerate.

Given the urgent need for new HIV prevention tools to slow the steady march of 50,000 new infections that occur each year in the US, Project Inform urged the advisory committee to recommend approval and has submitted written testimony to the FDA in support of approval of Truvada for PrEP. As is true of most other advocacy groups that have followed PrEP closely, we certainly have concerns about issues ranging from how best to support people to actually adhere to daily use of Truvada and also continue to use condoms during sex, as well as the possibility of long term side-effects from use of this medication. We feel, however, that these concerns can be addressed both through rigorous implementation studies and through post-approval activities Gilead should develop to monitor people's well-being on PrEP.

The FDA does not have to follow the advice of its advisory committee, which was made up of outside experts and decided that the benefits of a PrEP indication out-

weigh any potential risks. The agency has until mid-June to issue a final decision on this question.

Is PrEP dead in the water if the FDA fails to approve it? Not exactly, the drug is currently available by prescription in the United States. Doctors can prescribe Truvada for PrEP right now, and some have. The problems with a lack of approval by the FDA are numerous and serious, however.

Without approval, there is no official guidance for clinicians to follow regarding how to correctly prescribe PrEP and which populations this strategy is most likely to benefit. Safety measures, including a registry to track possible long-term problems, including side effects and the development of drug resistance, cannot be put in place. What is more, FDA approval will heavily influence whether or not public and private insurers agree to cover this medical intervention, creating the possibility that only those who can afford to pay for PrEP on their own or who have excellent insurance coverage will have access to this important prevention opportunity. PrEP is particularly needed by young gay and bisexual Black and Latino men, for whom access will almost certainly be minimal without FDA approval.

Project Inform does not believe that PrEP is for everyone at risk for infection. It is a serious medical intervention, and a costly one, as well. But we believe strongly that PrEP can benefit many people who will otherwise become infected with HIV. And we believe even more strongly that people at risk for acquiring HIV have a right to choose from among a set of safe and effective prevention methods that can best support their efforts to remain HIV-negative.

If you would like to add your voice to Project Inform's on this important issue, please visit www.avac.org/ht/a/GetDocumentAction/i/42405 for directions. For further information about PrEP data, visit www.projectinform.org/news/prep-at-croi-high-efficacy-but-adherence-is-critical/.

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Project Inform Partners to Help Launch 877-HELP-4-HEP

Alan McCord, Director of Education
amccord@projectinform.org

The past two years have seen the introduction of new medications to treat and even cure hepatitis C. It is reasonable to expect that coming years will see additional medications that simplify and shorten treatment even further, and that cure infection completely. In this new clinical environment, it is important that people at risk for hepatitis C infection and those who test positive have access to high quality, unbiased testing, care and treatment information.

The 877-HELP-4-HEP support line was launched on February 1 of this year by The Support Partnership (TSP), a collaboration of five national hepatitis C organizations, including Project Inform. Run by and for people affected by hepatitis C, this national resource provides information, referrals and a call-back service to support individuals in their decisions to manage their hepatitis C health.

HELP-4-HEP phone counselors are trained to answer general questions about hepatitis C risk, transmission, blood work, medical care and treatment. They also assist people in coping with their health status, finding ways to cover the costs of treatments and care, providing referrals to appropriate local services, and supporting them throughout treatment, which can be a challenging experience for many.

Already, the support line has responded to a full range of issues faced by people with hepatitis C. Unfortunately, what often complicates people's ability to make health decisions are significant social issues, including struggles with disclosing one's status to loved ones or dealing with stigma, social isolation and rejection suffered by people who have this disease.

A unique feature of HELP-4-HEP is the call-back service that phone counselors offer. The support line can provide linkage to care and other support services over time, helping to move callers step by step through their personal continuum of care. Using 877-HELP-4-HEP in this way helps people with hepatitis C navigate their way through the complexities of screening, diagnosis, medical evaluation, treatment and health maintenance.

HELP-4-HEP has supported some 200 people with quality information and referrals within our first two months of service. It has supported many of these callers to cope with telling their friends and family and advocate for themselves with their doctors. So far, counselors are making call-backs to about

one-quarter of our callers to follow up on their progress and to ensure they are supported throughout their journey. We hope to serve thousands more within our first year of operation.

The toll-free 877-HELP-4-HEP (877-435-7443) operates Monday through Friday, 9 a.m. to 7 p.m. EST. We encourage *In Focus* readers to share this phone number with anyone they know who might benefit from this great service.

To learn more, visit www.help4hep.org. TSP includes HealthPro (formerly Hep-C ALERT) in Florida; Hepatitis C Association in New Jersey; Hepatitis Education Project in Washington state; Hep C Connection in Colorado; and Project Inform.



In Memory of Joe Rosenthal

We are saddened to announce the loss of Joe Rosenthal, who passed away April 7. After a distinguished career in library science in New York and Berkeley, Joe volunteered as an operator on Project Inform's HIV Health InfoLine for several years. He was a generous philanthropist not only to Project Inform, but many other library, arts and education entities in the Bay Area. His gentleness, community involvement and bright disposition will be missed.



Two Things Everyone Can Do to End HIV& Hepatitis C

Dana Van Gorder, Executive Director
 dvangorder@projectinform.org

As it has been since the first day HIV emerged as a major threat, the condom continues to be one of the two most effective tools we have for preventing HIV transmission, responsible for preventing massive numbers of cases of HIV. The other, of course, is the sterile syringe when used by injection drug users. Millions of people have found condoms relatively acceptable and easy to use in the face of the risk of acquiring or transmitting HIV. Many other people find condoms unacceptable and difficult to use some—or all—of the time. Ours is not to judge, but to try to persuade.

Even as we advocate for medical forms of HIV prevention such as treatment as prevention or Pre-Exposure Prophylaxis, Project Inform believes in the primacy of the condom. Both of these effective forms of medication-based prevention are only 100 percent effective when combined with condom use.

So it is that I lament the absence today of creative efforts to once again promote condom use among gay men and others at risk for HIV. Recently, I attended a White House conference on HIV at which a featured speaker said what has become the norm among people working in HIV today. “We all know that sex without condoms feels better. We all know that condoms are a barrier to intimacy and love.” A complete capitulation to the idea that efforts to reframe condoms as a good thing would be a waste of time and resources.

Not so fast.

What about the idea of reframing sexual pleasure as including the absence of worry? It feels better, and is actually more fun, to have sex without anything to worry about! What about the idea of reframing condoms as the epitome of intimacy? Two people taking steps to protect one another from harm is, after all, a very caring, loving and intimate act. What about any visible effort to promote condom use again, at all?

We aren’t likely to see any large advertising campaigns revisiting or encouraging condom use any time soon. But each of us who may think badly about them could reconsider the way we think about condoms. And each of us could have a conversation with people we care about to see how they regard the condom, and whether they could view

them in a new light that results in using them more often.

At the same time, each of us could also have a conversation with friends and loved ones about the importance of knowing their HIV or hepatitis C status. Ending both epidemics now depends heavily on identifying everyone who currently has either virus, and linking them to quality care and treatment as quickly as they are willing and able. But even though we have come a long way in public attitudes about both diseases, it is still very difficult for many people to face a diagnosis of HIV or hepatitis C. Positive people fear—and sometimes actually suffer—the loss of important or potential relationships as a result of discovering that they carry either virus.

The antidote is for friends and loved ones to ask those they think may benefit from taking an HIV or hepatitis C test whether they have done so recently, and explore any reasons why they have not. Above all, it is essential that we make it clear that we will be supportive no matter what the result. It can’t hurt to offer to go to a testing appointment with someone if that is what will help them to take this important step.

Together, these two acts of caring, taken by each and every one of us, would play a significant role in ending these two unnecessary epidemics.

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 July 15, 2012 • Golden Gate Park**

100% of funds raised go to support PI's work!

Project Inform Financial Information

(for the year ending June 30, 2011)

These figures are excerpted from the audited financial statements for the fiscal year ending June 30, 2011.

ASSETS	2011	LIABILITIES AND NET ASSETS	2011
Current Assets		LIABILITIES	
Cash and Equivalents	\$422,213	Current Liabilities	
Investment - Under One Roof	-	Accounts Payable	\$ 7,931
Grants Receivable	\$104,947	Accrued Expenses	\$53,206
Assets Held by Others	\$206,904	Fees Received in Advance	\$10,925
Prepaid Expenses	\$20,003	Total Current Liabilities	\$72,062
Total Current Assets	\$754,067		
Noncurrent Assets		NET ASSETS	
Assets Held by Others	\$890,911	Unrestricted	\$338,721
Deposits	\$6,169	Temporarily Restricted	\$1,248,015
Property and Equipment - Net	\$ 7,651	Total Net Assets	\$1,586,736
Total Noncurrent Assets	\$904,731		
Total Assets	\$1,658,798	Total Liabilities and Net Assets	\$1,658,798

10 Ways You Can Support Project Inform's Work:

Keep up with HIV/AIDS and hepatitis C issues and news by following Project on Facebook or Twitter.

Set up a recurring monthly or quarterly gift to be deducted from your credit or debit card.

Throw a House Party (or brunch or movie party) and collect donations to support Project Inform's work.

Consider leaving a portion of your estate to Project Inform and leave a legacy to improve the lives of those living with HIV/AIDS or hepatitis C.

Volunteer for Project Inform. We're a small staff so we'd love your help!

Give via your company's matching gift program.

Eat + Shop. Support Project Inform while shopping or eating at select stores or restaurants throughout San Francisco.

Attend an event sponsored by or for Project Inform. Events raise awareness and funds to support underserved populations living with HIV/AIDS and hepatitis C.

Sign up for our PI Action Network. Join hundreds of other public policy advocates in notifying legislators know you are concerned about HIV/AIDS and hepatitis C issues.

Donate your car to Project Inform. We have a system in place that requires very little effort on your part!

Visit projectinform.org or email Jenn Heflin at jheflin@projectinform.org to find out about any of these ways to give!

Save the date for Evening of Hope 2012

A Night of Life Saving Fashion

October 24, 2012

6pm-midnight
City View at Metreon
Tickets \$200 | Host Level Starts at \$500

projectinform.org/fashion

Project Inform Staff

Ryan Clary
Director of Public Policy

Anne Donnelly
Director of Health Care Policy

David Evans
Director of Research Advocacy

Jenn Heflin
Development Manager

Henry Lucero
Deputy Executive Director for Development

Alan McCord
Director of Education

Sarah Smith
Agency Administrator

Dana Van Gorder
Executive Director

Board of Directors

Andrew Bosco

Fred Dillon
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Christopher Esposito
President

Ferdinand Garcia
Vice President

Stephen Harris

Shane Humphreys

Tom Kelley
Emeritus

Mark Illeman

Catherine Jane Mendoza

Ricky Shankar
Treasurer

Brenden Shucart

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INFORM
273 9th Street
San Francisco, CA

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PROJECTINFORM.ORG/FASHION