POSITIVELY PALM BEACH

Treasure Coast Health Council, Inc.
600 Sandtree Drive | Suite 101
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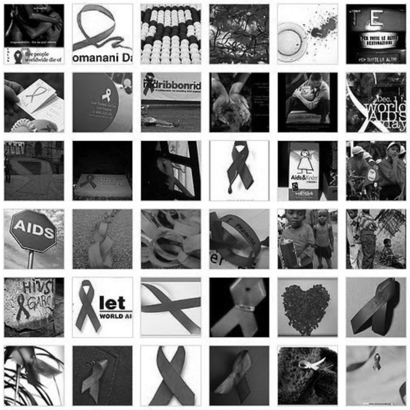

Increasing Access to Health Care for People Living With HIV: We Need Your Help

By Georgina Verdugo, *Director, Office for Civil Rights (OCR), U.S. Department of Health and Human Services (HHS)*

Earlier this week, OCR entered into a settlement agreement with the Windsor Rosewood Care Center, LLC (WRCC), a Contra Costa County, California nursing home, which agreed to provide individuals living with HIV equal access to its facility, as required by Federal law. This settlement resulted from a discrimination complaint initiated by a case manager who reported that two months before her client died, he was denied admission to the Contra Costa nursing home because he had AIDS. (When we use the term “living with HIV,” we mean both AIDS and HIV-positive status).

A few years ago, OCR entered into a similar settlement with the A.T. Associates nursing home chain in Alameda County, California. That settlement resulted from a discrimination complaint initiated by a hospital social worker who also reported that her client had been denied admission to a nursing home because he is HIV-positive.

In the 1980s, many of our families were touched by AIDS and we lost many young colleagues and friends. Today, we are grateful that as treatments improve, more individuals with HIV are leading long lives and becoming seniors. Some of these seniors, inevitably, will need nursing home care.

At OCR, we will not tolerate nursing homes which deny admission to individuals solely because they are HIV-positive. The Department of Health and Human Services is committed to ensuring access to health care for all Americans; and OCR will act diligently to eliminate unlawful discrimination in health care settings, including public and private nursing homes. But to do that, we need your help.

As the Windsor Rosewood and A.T. Associates nursing home cases illustrate, for us to do our work at OCR, we need to hear from people living with HIV and their advocates, including their attorneys, social workers, and case managers.

OCR is the sole HHS agency with the authority to enforce Section 504 of the Rehabilitation Act of 1973 (Section 504), which prohibits disability discrimination in programs or activities receiving Federal financial assistance, including Medicaid and Medicare Part A reimbursements; and the Americans with Disabilities Act of 1990 (the ADA), which prohibits disability discrimination by state and local government agencies, such as state-operated nursing homes. Federal courts have long held that AIDS and HIV-positive status are disabilities for purposes of Section 504 and the ADA.

If you feel that a nursing home, hospital, doctor, or other health care provider receiving federal financial assistance from HHS, or a state or local government agency, has discriminated against you (or your client, relative or friend) on the basis of race, color, national origin, age, or disability (including AIDS and HIV-positive status), you may file a discrimination complaint with the HHS Office for Civil Rights.

If you file a discrimination complaint with OCR, one of our ten Regional Offices will investigate your complaint. If OCR concludes that the health care provider or local agency has discriminated against you, then OCR will issue a Violation Letter of Finding. The provider or agency will be given an opportunity to resolve the Violation Letter of Finding through settlement. If the provider or agency is not willing to settle, OCR has the authority to initiate enforcement proceedings to suspend Federal financial assistance, including Medicaid and Medicare Part A reimbursements, to the provider or agency.

The bottom line is that OCR will diligently investigate discrimination complaints filed by individuals living with HIV. If you are an advocate, attorney, social worker, case manager or an individual living with HIV, we want to hear from you and we need your help to protect the civil rights of all Americans.

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Putting TLC+ to the Test

By Carl W. Dieffenbach, Ph.D., Director of NIAID Division of AIDS

Carl W. Dieffenbach, Ph.D.

If we routinely test everyone for HIV and treat those who are infected, could we bring an end to the HIV/AIDS epidemic? The test and treat concept, modeled on data from South Africa by scientists at the World Health Organization, is a provocative HIV prevention strategy. According to mathematical modeling, a successfully implemented test and treat program could significantly reduce the number of HIV infections in South Africa within 10 years. While a growing number of experts within the HIV/AIDS community are intrigued at the possibility, no one knows whether this strategy would work in the real world.

The National Institutes of Health (NIH), the premier research institution of the U.S. government, is taking steps to find out. NIH is planning a 3-year study in 6 major U.S. cities. Called TLC+ (for Enhanced Test, Link to Care Plus Treat Strategy), this study will explore the feasibility of expanding HIV testing, better linking those who test HIV positive to medical care and treatment, and improving adherence to HIV treatment. The components of TLC+ will be evaluated against the current standard of HIV testing and treatment.

It's effectiveness will depend on a number of key factors. For starters, TLC+ requires a high level of acceptance and commitment to routine HIV testing. Changing public perception is never easy, so we'll need various forms of social marketing to help lay the groundwork for a more supportive environment. The success of TLC+ also hinges on the ability to reach at-risk individuals. Outreach will be critical, so expanding HIV testing services at strategic sites such as emergency rooms and hospital admission desks is a good place to start.

The next critical component of TLC+ is successfully linking newly diagnosed individuals into care and treatment. Unfortunately, many people don't make it to their follow-up medical visits for a variety of reasons. Yet these individuals can continue to spread the virus in their communities until we entice them to step through the door, whether it's giving them a pat on the back or offering financial incentives.

Finally, all HIV-infected individuals, regardless of disease stage, need to start antiretroviral therapy (ART) when they and their health care provider decide it's the right time. Equally as important as starting, they need to faithfully adhere to their drug regimens to ensure good health, low risk of HIV-related complications and reduce the risk of developing drug resistance. We know that ART can dramatically lower the level of the virus in the blood to undetectable levels, which may reduce the risk of HIV transmission. This is a crucial step in the TLC+ strategy that will hopefully pay future dividends in reducing the spread of HIV in communities.

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Look who's talking now!!

Sonja Swanson Holbrook, MPH

Message from the Ryan White Program Manager

Sonja Swanson Holbrook, MPH
Ryan White Program Manager

I began working with Palm Beach County at the Department of Community Services on March 22nd. With the Ryan White grant award arriving around that same time, there has been a whirlwind of activity in our office. I am happy to report that we received a grade of 91% on our grant application. The total grant for our area this year is $9,058,569 which is a 5.7% increase ($485,369) over last year's grant award ($8,573,200). It is a very exciting time to begin working as the Ryan White Program Manager.

I am looking forward to working with each of you in my new capacity. Over the past nine years I have interacted with many of you through my work supporting the efforts of the CARE Council, most recently as the Health Planning Manager. Over the years we have experienced many changes with the HIV system of care nationally, as well as locally here in Palm Beach County. There have been good times and a few rough patches. We have seen many friends come and go. Recently we have experienced many changes in staffing and leadership roles. The friends that have moved on will be missed.

Looking ahead, there are several new and exciting things on the horizon. The CARE Council has recently allocated funds for a Peer Mentor Program. This is an exciting opportunity to implement a peer based program that the federal and state governments have been encouraging local areas to incorporate into their HIV/AIDS system of care.

In addition, we are working on a needs assessment this year. Every three years a county-wide needs assessment is conducted to assess the needs of the HIV community. 365 surveys from people living with HIV/AIDS (PLWHA) in Palm Beach County have been collected by trained data collectors. This summer focus groups will be held among several special populations. These data assist the CARE Council as they plan to meet the needs of PLWHA in our county, by prioritizing service categories and allocating funding for each service category. These data also allow us to identify service gaps, and assess the overall functioning of the HIV/AIDS system of care.

While change can be uncomfortable and scary sometimes, I think that most of the time it is an opportunity for growth. I am looking forward to the year ahead. As always the medical care of persons living with HIV/AIDS is why the Ryan White program exists. I am committed to the goal of bringing all persons living with HIV/AIDS in to care.

Sonja Swanson Holbrook may be contacted through the Palm Beach County Department of Community Services, 810 Datura Street, West Palm Beach, FL 33401, 561-355-4730, SHolbroo@pbcgov.org.

Presidential Memorandum - Hospital Visitation

MEMORANDUM FOR THE SECRETARY OF HEALTH AND HUMAN SERVICES

SUBJECT: Respecting the Rights of Hospital Patients to Receive Visitors and to Designate Surrogate Decision Makers for Medical Emergencies

There are few moments in our lives that call for greater compassion and companionship than when a loved one is admitted to the hospital. In these hours of need and moments of pain and anxiety, all of us would hope to have a hand to hold, a shoulder on which to lean -- a loved one to be there for us, as we would be there for them.

Yet every day, all across America, patients are denied the kindnesses and caring of a loved one at their sides -- whether in a sudden medical emergency or a prolonged hospital stay. Often, a widow or widower with no children is denied the support and comfort of a good friend. Members of religious orders are sometimes unable to choose someone other than an immediate family member to visit them and make medical decisions on their behalf. Also uniquely affected are gay and lesbian Americans who are often barred from the bedsides of the partners with whom they may have spent decades of their lives -- unable to be there for the person they love, and unable to act as a legal surrogate if their partner is incapacitated.

For all of these Americans, the failure to have their wishes respected concerning who may visit them or make medical decisions on their behalf has real consequences. It means that doctors and nurses do not always have the best information about patients' medications and medical histories and that friends and certain family members are unable to serve as intermediaries to help communicate patients' needs. It means that a stressful and at times terrifying experience for patients is senselessly compounded by indignity and unfairness. And it means that all too often, people are made to suffer or even to pass away alone, denied the comfort of companionship in their final moments while a loved one is left worrying and pacing down the hall.

Many States have taken steps to try to put an end to these problems. North Carolina recently amended its Patients' Bill of Rights to give each patient "the right to designate visitors who shall receive the same visitation privileges as the patient's immediate family members, regardless of whether the visitors are legally related to the patient" -- a right that applies in every hospital in the State. Delaware, Nebraska, and Minnesota have adopted similar laws.

My Administration can expand on these important steps to ensure that patients can receive compassionate care and equal treatment during their hospital stays. By this memorandum, I request that you take the following steps:

1. Initiate appropriate rulemaking, pursuant to your authority under 42 U.S.C. 1395x and other relevant provisions of law, to ensure that hospitals that participate in Medicare or Medicaid respect the rights of patients to designate visitors. It should be made clear that designated visitors, including individuals designated by legally valid advance directives (such as durable powers of attorney and health care proxies), should enjoy visitation privileges that are no more restrictive than those that immediate family members enjoy. You should also provide that participating hospitals may not deny visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, or disability. The rulemaking should take into account the need for hospitals to restrict visitation in medically appropriate circumstances as well as the clinical decisions that medical professionals make about a patient's care or treatment.

2. Ensure that all hospitals participating in Medicare or Medicaid are in full compliance with regulations, codified at 42 CFR 482.13 and 42 CFR 489.102(a), promulgated to guarantee that all patients' advance directives, such as durable powers of attorney and health care proxies, are respected, and that patients' representatives otherwise have the right to make informed decisions regarding patients' care. Additionally, I request that you issue new guidelines, pursuant to your authority under 42 U.S.C. 1395cc and other relevant provisions of law, and provide technical assistance on how hospitals participating in Medicare or Medicaid can best comply with the regulations and take any additional appropriate measures to fully enforce the regulations.

3. Provide additional recommendations to me, within 180 days of the date of this memorandum, on actions the Department of Health and Human Services can take to address hospital visitation, medical decision-making, or other health care issues that affect LGBT patients and their families.

This memorandum is not intended to, and does not, create any right or benefit, substantive or procedural, enforceable at law or in equity by any party against the United States, its departments, agencies, or entities, its officers, employees, or agents, or any other person.

You are hereby authorized and directed to publish this memorandum in the Federal Register.

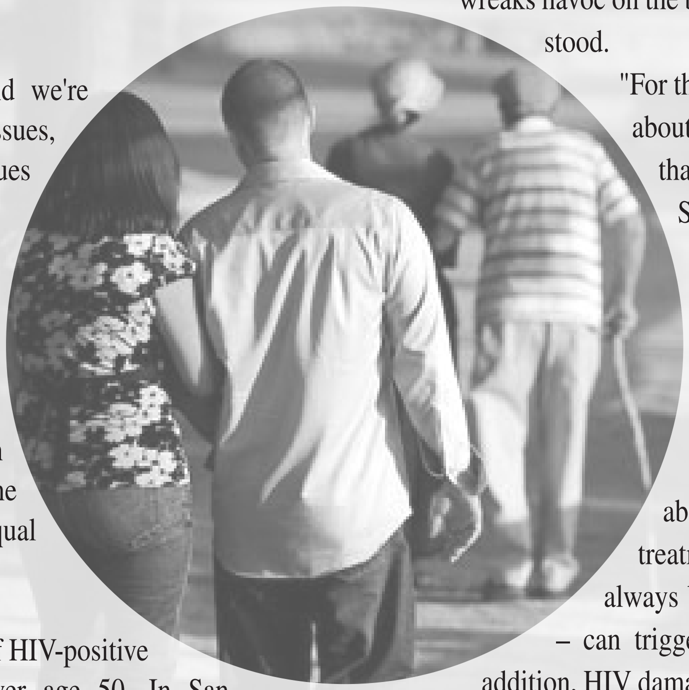
BARACK OBAMA

Project Inform forum focuses on HIV and aging

by Liz Highleyman

Aging has become a key focus for people with HIV and their health care providers, but much remains to be learned about the medical and psychosocial aspects of the aging process in this population, which was the topic of a recent forum sponsored by Project Inform.

"We're facing a paradox," said Matt Sharp, Project Inform's new director of treatment and prevention advocacy. Having lived with HIV for more than 20 years, Sharp, 53, described himself as one of the lucky survivors.



"Many of us are thriving and we're dealing less with AIDS-specific issues, but now we're dealing with issues that come with age," he noted.

Due to effective antiretroviral therapy, life expectancy of HIV-positive people in the United States has increased dramatically – more than doubling between 1996 and 2005, according to one recent study – but still does not equal that of the general population.

By the year 2015, nearly half of HIV-positive people in the U.S. will be over age 50. In San Francisco, that figure already stands at 40 percent. While about 15 percent of newly infected individuals are over 50, people who have lived with the virus for years or decades face distinct challenges.

At the forum, held September 24, Sharp reviewed some of the chronic conditions facing people with HIV as they age, including cardiovascular disease, liver disease (often related to hepatitis B or C), kidney impairment, non-AIDS cancers (including anal and cervical cancer caused by human papillomavirus), bone loss (osteoporosis), neurocognitive decline, and "frailty," characterized by weight loss, weakness, and increased risk of disability and death.

With opportunistic infections and cancers now seldom seen among people on antiretroviral treatment, management of age-related chronic conditions has become a mainstay of HIV medicine.

Accelerated aging?

A growing segment of HIV research aims to tease out the causes underlying the apparent acceleration of the aging process in long-term survivors.

Many of these problems have been blamed on antiretroviral therapy over the years, and various drugs do appear to play a role. But it is increasingly clear that long-term HIV infection itself wreaks havoc on the body in ways that are not fully understood.

"For the last 10 years we've been so excited about therapy helping people live longer that we've gotten a bit selfish," said Dr. Steven Deeks of San Francisco General Hospital. "We now want people to live a normal lifespan with completely restored health, but we're not there yet."

Even low-level so-called undetectable virus in people on effective treatment – which in fact can almost always be detected using ultrasensitive tests – can trigger persistent immune activation. In addition, HIV damages the gut lining during early infection, allowing bacteria to leak out and ignite system-wide inflammation. Antiretroviral therapy dramatically reduces immune activation and inflammation, but does not bring back the normal pre-HIV state.

Furthermore, having a lower CD4 T-cell count has been linked to higher risk of non-AIDS diseases among people who are well above the 200 cell "danger zone" for opportunistic infections, or even the current 350 cell threshold for starting treatment. And while CD4 counts usually rise after starting treatment, the new cells may not work as well as those that were lost.

Chronic low-grade inflammation appears to be the common denominator underlying all these conditions, according to Deeks. It is also increasingly implicated in age-related disease among HIV-negative people, demonstrating that long-term viral infection is only part of the puzzle.

While researchers continue to study the interactions between long-term infection and the aging process, HIV-positive people can take steps now to prevent disease and improve their overall health. These include quitting smoking, eating a healthy diet, getting more exercise, and avoiding or reducing use of alcohol and recreational drugs.

"You don't need to join a gym to exercise, you just need to get your blood moving for 30 minutes a day," said Sharp. He also emphasized the need for cancer screening – including anal Pap smears and colon cancer tests – and vitamin D and calcium supplements to maintain strong bones.

As with diabetics, Deeks said, HIV-positive people should be treated aggressively to prevent cardiovascular events – the leading cause of death for older people regardless of HIV status. This includes "getting cholesterol not just down to normal, but as low as possible." As an added benefit, the cholesterol-lowering statin drugs also have a general anti-inflammatory effect, but they can interact with some antiretrovirals.

Looking to the future, researchers are exploring therapies (such as IL-7) to boost T-cells, nutritional therapy to protect the gut, anti-inflammatory drugs to control chronic immune activation (potentially including the recently approved antiretroviral drug maraviroc), and strategies to eradicate the last bit of latent virus.

Psychosocial issues

Shifting the focus to psychosocial issues, Peter Carnini from New Leaf: Services for Our Community discussed the isolation and lack of social support older people with HIV often experience. Many older gay men feel invisible, he said, and there is a "disconnect" between older and younger HIV-positive men in the community.

Long-term HIV survivors, he added, may struggle with what he called "fragmented life narratives" as they live longer than they ever expected, having not made plans for the future such as completing their education or saving money.

Other common issues facing older HIV-positive men include estrangement from families of origin, "survivor guilt," post-traumatic stress related to dealing with a life-threatening illness and frequent bereavement, changes in sexual desire and function, and difficulties with employment, finances, and insurance. Many of these issues, he noted, seem to be more acute for men of color.

"Often when we hit 40 or 50, it becomes a little more difficult to make friends, we don't go out as often, and isolation sets in," Carnini concluded. "Older gay men with HIV need to become more visible. This won't happen if you put your dinner in the microwave and turn on TV. It isn't going to change unless we change it."

MEDICARE EXPANDS COVERAGE FOR TREATING FACIAL LIPODYSTROPHY SYNDROME IN PEOPLE LIVING WITH HIV

The Centers for Medicare & Medicaid Services (CMS) today announced its decision to cover facial injections for Medicare beneficiaries who experience symptoms of depression due to the stigmatizing appearance of severely hollowed cheeks resulting from the drug treatment for Human Immunodeficiency Virus (HIV). Today's decision is effective immediately.

Facial lipodystrophy (LDS) is a localized loss of fat from the face, causing an excessively thin appearance in the cheeks. In some cases, facial LDS may be a side effect of certain kinds of medications (antiretroviral therapies) that individuals receive as part of an HIV infection treatment regimen.

The facial LDS can leave people living with HIV looking gaunt and seriously ill, which may stigmatize them as part of their HIV-infection status. Individuals who take these medications and experience facial LDS side effects may suffer psychological effects related to a negative self-image. These effects may lead people living with HIV to discontinue their antiretroviral therapies. The new decision allows for treatment of individuals who experience symptoms of depression due to the appearance changes from facial LDS.

The injections included in today's coverage decision are "fillers" that have been approved by the U.S. Food & Drug Administration (FDA) to be injected under the skin in the face to help fill out its appearance specifically for treatment of facial LDS. Data show that these injections can improve patient self-image, relieve symptoms of depression, and may lead to improved compliance with anti-HIV treatment.

"Today's decision marks an important milestone in Medicare's coverage for HIV-infection therapies," said Barry M. Straube, M.D., CMS Chief Medical Officer and Director of the Agency's Office of Clinical Standards & Quality. "Helping people living with HIV improve their self-image and comply with anti-HIV treatment can lead to better quality of life and, ultimately, improve the quality of care that beneficiaries receive."

May 2010

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June 2010

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May

17
6:30 p.m.
NA Meeting
Compass

4p.m.-7:30p.m.
FREE Rapid Oral HIV Testing
Compass

18
1 p.m.-5:30 p.m.
FREE Rapid Oral
HIV Testing
Compass

19
11:00 a.m.
Da Group
Peer Led Support Group
United Deliverance

11:00 a.m.
Drop In Center Potluck Support Group
CAP
Palm Springs

7:30 p.m.
BrothasSpeak
Support Group
Compass

20
4p.m.-7:30p.m.
FREE Rapid Oral HIV Testing
Compass

8:00 p.m.
Positive Living Support Group
Compass

21
6:30p.m.
CHANGE
Orientation
Compass

24
6:30 p.m.
NA Meeting
Compass

4p.m.-7:30p.m.
FREE Rapid Oral HIV Testing
Compass

25
1 p.m.-5:30 p.m.
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Da Group
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Orientation
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FREE Rapid Oral HIV Testing
Compass

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CHANGE
Orientation
Compass

Cucumber, Tomato and Mozzarella Salad

1 Serving

This simple salad is a version of an Italian standard. You'll find fresh, white mozzarella cheese in most delis or supermarkets - it's very different from the pale yellow, packaged mozzarella.

Ingredients:

1 tbsp balsamic vinegar
1/2 tbsp quality extra-virgin olive oil
1 clove garlic, minced
1/2 cucumber, peeled and seeded
1 large Roma tomato, sliced
1 oz fresh mozzarella cheese
3 leaves fresh basil, chopped

Nutritional Information:
Per serving:

137 calories
10 g total fat (1 g sat)
20 mg cholesterol
7 g carbohydrate
6 g protein
1 g fiber
27 mg sodium

Instructions:

Mix the balsamic vinegar, olive oil and garlic in a small bowl. On a salad plate, layer slices of the cucumber, tomato and cheese. Drizzle with the dressing. Sprinkle with the chopped fresh basil.

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