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Excerpts from Hotline Memos of April 2002
From Project Inform

What’s New in Treatment Information?

Expanded Access Program for Atazanavir
Bristol-Meyers Squibb, the developers of a once-daily protease inhibitor, atazanavir, will start the first phase of large expanded access program around May 15.

To qualify, people must meet the following criteria:
- be 16 or older
- a viral load over 5,000 while on HAART
- CD4+ count below 300
- Unable to construct a HAART regimen due to one or more of the following:
  - Previous treatment failure on HAART
  - Significantly high triglycerides or lipids
  - Other toxicity or intolerance, as defined by the protocol
  - Drug-drug interaction
- OR -
  - HAART-related high lipid levels that are unresponsive to lipid-lowering agents, regardless of viral load or CD4+ count

Some exclusions will also affect applicants, including:
- Current use of Kaletra, Crixivan or Sustiva (due to lack of drug interaction)
- Underlying heart disease or irregular heart beat

The requirements may change over the course of the program as new information becomes available. To register patients in the program, physicians should call 1-877-726-7327.

What’s New in Public Policy?

Getting Started in Federal Policy Advocacy
The following was posted by Project Inform’s public policy department on a listserv for treatment advocates. It contains suggestions for how individuals can get involved in public policy advocacy at the federal level. For more information, contact Ryan Clary, 415-558-8669 x215 or tan@projectinform.org.

There are many national, regional, and local organizations and coalitions that advocate at the federal level. One coalition that pulls together a broad spectrum of organizations is the National Organizations Responding to AIDS. NORA is a coalition of national and local organizations that creates the appropriations agenda each year, determines the amount needed for each HIV/AIDS program and advocates for those funding figures throughout the year. There are some very active subcommittees in this coalition (including research, international issues, and overall appropriations) that are doing very substantive work. AIDS Action in Washington, DC coordinates NORA. Anyone who might be interested in that group should check out their website, www.aidsaction.org.

For those interested in researching a variety of opportunities to get involved in policy advocacy, a resource list of national organizations doing public policy advocacy is available. Please call or email tan@projectinform.org for a copy. It will soon be available on Project Inform’s website, www.projectinform.org/fs/resources.html#policy.

This list provides descriptions of the type of policy work these groups are doing, along with websites and phone numbers. We encourage anyone interested in getting involved with policy advocacy to check out the information on that resource list. There are many groups that focus on particular programs or issues. For a copy of this resource list, contact Ryan Clary at 415-558-8669 x215 or tan@projectinform.org.

There is great interest in advocacy around the AIDS Drug Assistance Program (ADAP). ADAPs around the country are having trouble meeting the needs of those who rely on them for drug access. ADAP has received an insufficient increase in federal funding the last two years, and President Bush’s proposed budget for the next fiscal
year calls for no increase. We must advocate strongly with Congress for adequate funding as the process unfolds this year. There are of course other factors contributing to the ADAP crisis, including drug price increases, insufficient contributions by state legislatures, increase in demand, and the wonderful fact that many people are living longer, thus relying on the program for more time. The ADAP Working Group is a coalition of pharmaceutical industry representatives and community organizations with a focused mission of securing adequate ADAP funding at the federal level. We are also trying to address some of the other factors listed. More community organizations are needed in this group, and individuals are needed to help advocate with their own representatives. If you are interested in getting involved with ADAP advocacy as an organization or an individual, contact Ryan Clary at Project Inform.

People can also get involved by joining Project Inform’s grassroots network, the Treatment Action Network (TAN). We send action alerts via email on a fairly regular basis on federal legislative and budget issues, with a focus on treatment, prevention, housing, and access issues. We always include contact information and a sample letter. It’s based on the philosophy that those most affected by the epidemic should be aware of what their elected officials are doing and how they can make sure their voice is heard. It is not the only grassroots network out there, and we suggest joining as many as possible. If you want to join the TAN email list, either sign up through our webpage at http://projinf.fauldhouse.com/tanlist/tanlist.php4 or send an email to tan@projectinform.org.

Finally, individuals can participate in advocacy by attending AIDSWATCH 2002. This is a three day event in Washington, D.C., organized by the National Association of People With AIDS in conjunction with other national, regional, and local organizations. The purpose of AIDSWATCH is for people living with HIV and their advocates to meet directly with their federal representatives and/or their legislative aides to talk about the need for adequate funding for all care/treatment, research, prevention, housing, and international programs. This year, AIDSWATCH will be held on June 9-11. The 9th is a briefing on the issues and tips on how to have an effective legislative meeting. On the 10th and 11th, participants will go with others from their state or region to meet with their U.S. Representative and two Senators (or their staff, who are very important to meet with), as well as others who may represent districts close to them. It is not important to be an expert on the issues. There will be a facilitator for the meeting who will be familiar with the specific funding requests. The point is to bring personal stories so that your elected officials understand how their actions affect you and other people they represent.

If you’re interested in attending AIDSWATCH, go to NAPWA’s website at www.napwa.org or email aidswatch@napwa.org.

What's New in Outreach?

California Statewide Treatment Education Program (CSTEP) pilots training for HIV educators

CSTEP is a collaborative training effort between Project Inform and the Asian and Pacific Islander Wellness Center (APIWC) funded through a grant from the California Department of Health Services Office of AIDS. The goal of CSTEP is to enhance the health of HIV-positive people from communities disproportionately affected by AIDS epidemic by increasing the ability of the HIV service providers working within these communities to support client access and utilization of HIV prevention, testing, care and support services. CSTEP trainers utilizes an active training approach centered in the practical application of HIV-related information and skills. Currently there are three levels of training for different types of providers ranging from outreach workers to HIV health educators working in community and clinical settings.

In March and April, the program piloted a five-day training specifically geared towards HIV educators in San Francisco and Los Angeles. As one trainee reflected, “After having a few days to digest the training...I have to honestly say that I thought that it was simply amazing! I feel like I have learned so much valuable information...You have provided me with sound tools to use in my daily applications and interactions with clients.” If you are a health or service provider working in the state of California and are interested in learning about CSTEP, please contact Claire Wingfield at 415-292-3400 or www.cstep.org. All of the CSTEP trainings are FREE.

Welcome New Hotline Operators - April Hotline Training

Dedicated and caring volunteer operators who have successfully completed a specialized training program staff the Project Inform National HIV/AIDS Treatment Information Hotline. In April, Project Inform held a Hotline training and welcomed six new operators to our volunteer team. Hotline hours are Monday - Friday 9am-5pm and Saturday 10am-4pm Pacific Time. Hotline operators are trained to answer questions about HIV-related care and treatment options as well as refer callers to local services available in their areas. If an operator cannot answer a caller’s question, he or she works with Project Inform staff to research and get back to the caller more in-depth information.

The Project Inform Hotline program is an integral part of Project Inform’s mission to provide information on the care and treatment of HIV disease and to inspire people to make informed choices and to choose hope over despair. If you live in the San Francisco Bay Area and would like to volunteer with Project Inform’s Hotline program, contact Mark Owens 415-558-8669 x218.