

TABLE OF CONTENTS

FEATURES

- 8 HIV SPECIAL NEEDS PLANS (SNPs)**
A New Health Care Option in New York
By Doug Wirth
- 18 CHALLENGES WHEN STARTING ANTIRETROVIRAL TREATMENT**
Tips for Initiating and Adhering to a Medication Regimen
By Laurie Newman and Carmen Rodriguez
- 22 A COMPREHENSIVE TREATMENT APPROACH TO HIV**
Reducing Toxicity, Including Micronutrients, and Maintaining Effectiveness
By Jon Kaiser

DEPARTMENTS

- 2 LETTER FROM THE EDITOR**
- 3 FROM THE EXECUTIVE DIRECTOR**
- 4 THE BODY POSITIVE CREED**
"You Are Not Alone"
- 28 Medical Matters**
Factors Influencing Non-Adherence
- 30 Psychologically Speaking**
"It's Not Only About the Pills"
By Gary R. McClain
- 36 Healthy Living**
Maximizing Medication Benefits with Natural Therapies
by JoAnn Yanez
- 39 Ads & Announcements**
- 40 Reader Survey**
Tell Us What You Think about Body Positive Magazine
- COVER:** Carlos N. Molina



Executive Director
Eric M. Rodriguez, Ph. D.

**Editor, Body Positive Magazine &
Agency Editor**
Raymond A. Smith, Ph. D.

**Art Director &
Editor SIDAahora**
Carlos N. Molina

Director of Programs and Services
Christopher Murphy, M.S.

Program Associate
Shakisha Wilson

Peer Coordinator
Steven Gordon

Peer Assistant
Chris Beattie

Peer Educators
Pedro Flores
Luz Hernandez
Michael Leatherbury
Lillyan Lubrano
Nancy Morales

Interns
Thy Pham-Cieliesz

Clinical Supervisor
Elizabeth Sloan-Power, M.S.W.

•
Founder
Michael Hirsch (1954-89)

•
Board of Directors
Richard Perz, Chair
Gregory Huang-Cruz, M.P.H., Vice Chair
Carol Harrison Catena, Secretary
Brian Walls, Treasurer
John P. Greco III
Joyce Hunter, D.S.W.
Mick Maurer, Ph.D., M.H.A
Patricia Shelton

•
National Advertising Representative
Rivendell Marketing - (212) 242-6863

Body Positive, inc.
19 Fulton St. Suite 308b
New York, NY 10038
phone: 212-566-7333
fax: 212-566-4539
helpline: 1-800-566-6599
www.bodypos.org

For back issues of Body Positive Magazine
and SIDAahora, visit: www.bodypos.org

Dear Readers,

Back when combination antiretroviral therapies were first introduced in 1996, they were both lifesavers and backbreakers. The first generation of HIV combination therapies were among the most demanding regimens in medical history. It was common to have to take dozens of pills many times a day, at carefully spaced intervals and with special dietary requirements. That first generation also caused all sorts of side effects, so that many healthier people with HIV felt worse on medications than off.

Thankfully, there have been a lot of advances in making HIV medications more tolerable, from fewer doses to better management of side effects to eased dietary restrictions. But managing HIV treatments is still a major challenge for most people, especially when they are dealing with other conditions or even just the ordinary problems associated with aging.

In this issue of **Body Positive Magazine**, our goal is to provide you with new information and ideas about how to maximize your HIV treatment while also maximizing your quality of life. Our lead story, on Medicaid Special Needs Plans (SNPs), tell us about an important new health care option for New Yorkers. Another key feature in this article is by Dr. Jon Kaiser, who offers insights into a “comprehensive treatment approach to HIV.” We also present a series of shorter articles about starting antiretroviral treatment, maintaining adherence, coping with the psychological demands of treatment, and the use of natural therapies.

This issue concludes with a Reader’s Survey. Your opinion is important to us, and we hope you’ll take the time to respond to a short survey, and possibly win a free three-year subscription to **Body Positive Magazine**. Please see page 40 for details...

Best,

Editor Raymond A. Smith

Art Director Carlos N. Molina

Contributing Writers

**Ronald F. Day; Edwin Krales; Gary R. McClain; Steve McMahon;
Frank Pizzoli; Gary Rosard; Ronald C. Russo; JoAnn Yanez**

Dear Readers,

Every HIV-positive person who is taking meds has their own tale of what it was like when they first started, and I am no exception. When I seroconverted five years ago, one of my greatest fears was of having to take handfuls of pills every day. The thought of debilitating short- and long-term side effects haunted me every time I had blood work done. But last year, when my numbers began to deteriorate rapidly and I had my first two opportunistic infections, my doctor at Callen-Lorde flatly informed me that I had to start taking meds immediately. After a few sleepless nights and long discussions with my partner, David, and my HIV-positive friends, I swallowed my fears and went on what my doctor said was the best and most successfully tolerated regimen to date – Kaletra and Combivir.

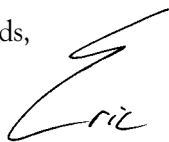
Problems arose for me immediately. Since I have trouble swallowing large pills, I just couldn't get those monstrous Kaletra horse pills down. It seemed easy enough for me to simply switch to the liquid form, but it tasted vile and made me violently ill all day. I was told that these side-effects would be temporary until my body got used to the medication, so I toughed it out for two miserable, gut-wrenching weeks. My doctor finally took pity on me and took me off of the Kaletra.

I was switched to a Sustiva-based regimen, and was really looking forward to the wild, vivid dreams that I'd heard so much about. Alas, no cool dreams for Eric. I was one of the lucky few who instead developed a crushing case of major clinical depression. I refused to leave my apartment and didn't answer the phone or go to work for three weeks. An alarmed and upset David finally called Callen-Lorde, and my doctor immediately took me off of the Sustiva. It was like someone had flipped a switch – within a week the depression had vanished and I was completely back to normal (no jokes please!).

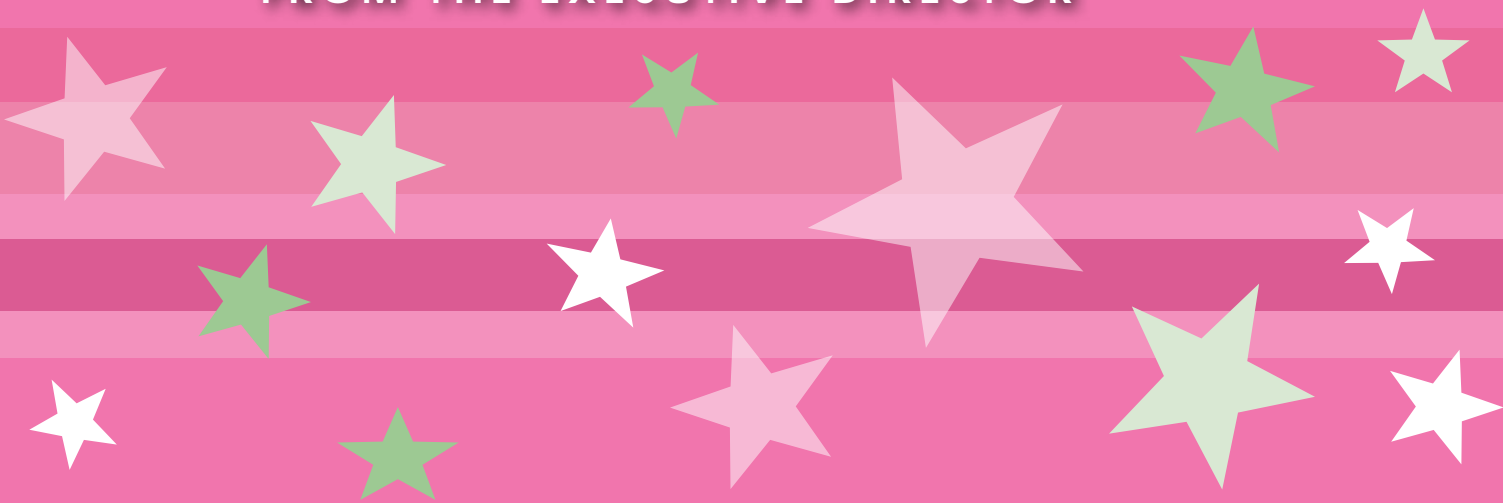
At this point my doctor switched me to my current regimen (Combivir, Viramune and Viread) and informed me that I was now being used as a case-study for HIV patients who have trouble acclimating to their meds (lucky me!). But now I am tolerating my current meds quite well, my numbers have improved dramatically, and I went through the initial adjustment period with very few side effects.

The moral of this story? Well, in hindsight, I can think of three lessons learned that I would like to share with you. First, don't be too embarrassed or afraid to talk to your doctor, as I had been. You'll just make yourself more miserable and suffer needlessly. Second, remember that HIV is a very individualized disease; a treatment that one person swears by may not work for you. And third, hang in there! With the support of loved ones, a stubbornly upbeat outlook, and a caring health care provider, you too can handle starting or switching meds. I hope that this issue of **Body Positive Magazine**, with its focus on managing your treatments, can offer some of the support and guidance you may need.

Warmest regards,



FROM THE EXECUTIVE DIRECTOR



You Are Not Alone

There are nearly a million of us in the United States.
Don't isolate yourselves.

BY MICHAEL SLOCUM AND JIM LEWIS

Maybe you have tested HIV-positive very recently; maybe you've known it for some time, but this is the first time you've reached out for information or support. You need to know that you are not alone. There are nearly a million HIV-positive people in the United States.

Testing positive for HIV does not mean that you have AIDS, but HIV is probably the greatest threat to your life you have ever faced. This virus may remain inactive in your body for a long time, but it may not. If you are healthy now, you may still go on to develop some sort of health problems related to HIV. You may develop AIDS. There remain many uncertainties surrounding HIV, and though there is currently no "cure" for HIV infection, there are treatments. You need to learn what information is available and make informed choices about your health.

Many HIV-positive people now live fulfilling and happy lives. Many are healthy and show no symptoms of disease. Many choose to take treatments and drugs that promise to lengthen their lives. So, as serious as this is, there is hope. You do not have to look at testing HIV-positive as if you've been given a death sentence.

It's a good thing you found this out. As upsetting as testing positive may have been for you, you are better off knowing, so you can learn about HIV and decide what you want to do about it. The fact that you cared enough about yourself to get the HIV test and the fact that you are reading this magazine show that you are concerned about your health. So give yourself some credit. You have taken important first steps to take care of yourself, and you should be glad about it.

Years ago, those who tested HIV-positive had few places to turn for support. These people felt like they were hanging in limbo. Fortunately, much has changed. We know more about HIV now, and many organizations have formed around the world to offer support and information to people living with this virus. Many have already faced the questions inherent in living with HIV, and many will follow. You don't have to face this by yourself. There are lots of hands reaching out to assist you.

Your Emotional Health. Finding out that you are infected is usually overwhelming. Even if you had suspected it for some time, learning that you are can be a traumatic experience. Testing HIV-positive has led some people to quit their jobs, quickly write out their wills, and say goodbye to their friends and family, only to discover that they aren't sick and will probably live for many years to come. It's common to perceive these results as an immediate death sentence, but this is simply not true.

What you are feeling now is perfectly normal. Anger, fear, confusion, numbness, depression—all are completely natural reactions to the kind of news you've heard. If you've

known for even several weeks, you may find yourself having a normal day, then suddenly remember that you are HIV-positive. It's common for this kind of realization to just "hit you in the face" out of nowhere over and over again. You are not going crazy if this happens to you. Your moods may swing from profound sadness one moment to extreme anger the next. That's normal, too.

The first step to getting through this emotional turmoil is to acknowledge what you are feeling. Don't be surprised to find yourself going through the day in a state of shock. Allow yourself to feel nothing. Your emotions will come rushing back soon enough. This is merely a way that your mind "turns off" to allow you to cope with a problem.

If you are feeling angry, that's fine. You have every right to be angry, and a lot to be angry about. This virus is threatening your very existence. It's okay to express this anger. If you're frightened, acknowledge your fears. You are thinking about things that would make anyone fearful. You are allowed to feel the way you do. Don't be hard on yourself or think you have to be strong. You don't have to be anything.

Fear of Sickness & Death. Almost everyone is afraid of getting sick and dying. If you're young, you may never have had to face the death of someone close to you. We often think of dying as something that happens only when we're old. You may never have really considered the reality of your own death before. Now, suddenly, you are HIV-positive and your mortality becomes very real. You may be afraid of pain, of hospitals, or of becoming unattractive to others through an illness.

Your reaction to the idea of getting sick or dying could go one of two ways. You may decide that you are definitely going to live and that there is no way that this virus is ever going to "get" you. This is a form of what's called denial — refusing to face some of the possibilities of living with HIV. If you find yourself feeling this way, try to keep in mind that having hope to go on with your life is good. However, it can become dangerous if it keeps you from taking care of yourself.

The other way you might choose to deal with the subject is by deciding that you are absolutely going to die of this and there is nothing you can do about it. If you go this way, you may find yourself fantasizing about your own sickness and death. You have to keep in mind that there are many people who are HIV-positive who are living productive, happy lives, and you can be among them if you choose. It's good to face up to the possible consequences of this infection, but not to the point that living today becomes less important than your fear of the future. It helps to remind yourself that everyone will die, but that doesn't prevent most people from living today.

Starting Over. One of the truths of testing HIV-positive is that once you know, you can never not know again.

Sustiva

From Previous Issue

Sustiva

For better or worse, your life will always be different now. You may be experiencing great feelings of loss about this. You may feel that certain areas of your life are now in the hands of doctors, insurance companies, or symptoms. This can make you feel as though you have less control over your own life and may cause you incredible anxiety.

Know this — you do not have to give up control of your life. By arming yourself with information and deciding what is right for you, you will soon realize that you are still the same person you were. It is your life, your body, your health, and no matter how well-meaning your family, your friends, or your doctor may be, they have no right to take control of your life. Allow yourself to take time to decide what you want to do. Then go do it.

You may find that many of the priorities in your life change rapidly. If you are considering making major changes in your life, just make sure that you think them through carefully. Many HIV-positive people have made huge changes in the way they live. Many have broken bad habits, such as drinking too much or smoking. Some have gotten out of bad relationships or quit jobs they really hated. Facing the possibility of getting sick or dying has made many of our lives much better because it has made us take action in areas we have previously ignored or repeatedly put off. Mortality can be a great motivator.

Some people blame themselves for being HIV-positive. This kind of guilt and self-hate is very destructive. Regardless of how you were infected, you did not go somewhere or do something with the intention of infecting yourself—so why beat yourself up about it? You are facing enough right now; you don't need to punish yourself for testing HIV-positive also.

Grief, or extreme sadness, is one of the emotions that most HIV-positive people face at some point. You may be grieving for yourself, facing the possibility of your own death. For many of us, the virus is not only affecting our lives, but the lives of those we love. Many have lost friends and loved ones to HIV, or have many people in their lives who are also HIV-positive. Allow yourself to express grief and fear in some way. Permit yourself to cry. These feelings are valuable and normal; ignoring them will not make them go away.

You may also feel that you are now damaged in some way—that no one will want to touch you or love you or that you are less desirable because you are HIV-positive. You may feel that you will never be able to love again, that no one would want to be with you if they knew that you were HIV-positive. These feelings will pass. You are not “damaged goods.” You are still a valuable person, as capable of giving

and receiving love as ever. You can make your own decisions, relax, and enjoy each day. This may be a struggle and you may have to find new ways of coping with daily life, but it's worth it.

Getting Support. Many of us have been raised with the idea of “rugged individualism,” that we must face things on our own, that this is what “strength” is all about. Asking for help or reaching out for support are often considered weaknesses. Consequently, a very common response to testing HIV-positive is withdrawal. We isolate ourselves, hiding the news of our status. This can be very painful.

Your life does not have to be doom and gloom. It is possible to have a very positive attitude as a person living with HIV—many are doing it right now—but it is much more difficult to get on with your life and live happily if you're trying to do it alone.

There's no need for you to handle this by yourself, and it's probably a mistake even to try to do it. You are not the only person facing this. Learn who the others are and what they have to offer. Just hearing how someone else has adjusted to living with the virus can be enough to help you realize that life is still good, that you can still have love and laughter. And you may also be surprised to learn that your own sharing can help others. In sharing the issues that concern us, each of our voices lends strength to the others.

Support groups, like those at Body Positive, are a powerful means of learning to cope with

this new beginning. There are support groups offered by HIV/AIDS organizations across the country. If you don't know of an HIV/AIDS organization in your area, call us at (212) 566-7333. If there's no support group in your area, you may be just the person to get one started. Just remember: those millions of people living successfully with HIV are people who've reached out to get the help they needed. Wherever you are, you can find support, or the means to create it. It just doesn't make sense for us to face the same issues without helping each other out. We are not alone. And neither are you.

Your life does not have to be doom and gloom. It is possible to have a very positive attitude as a person living with HIV— many are doing it right now—but it is much more difficult to get on with your life if you're trying to do it alone.

Michael Slocum and Jim Lewis were editors of Body Positive. HIV/AIDS organizations around the world have reprinted “You Are Not Alone” in their own languages.

HIV Special Needs Plans (SNP)

A New Health Care Option in New York

Since the beginning of the HIV/AIDS epidemic, advocates, consumers and providers have argued that comprehensive, high quality, health care for people living with HIV/AIDS (PWHAs) is a basic right. To achieve that goal, the New York State Department of Health AIDS Institute built an extensive system of HIV care largely utilizing the State's Medicaid program. Approximately 85% of persons with HIV receive health care through Medicaid during the course of their illness.

New York's Medicaid program is truly one of the most comprehensive health care programs in the country for PWHAs. Covered benefits and services include primary care, specialty care, inpatient hospitalization and emergency care, mental health and substance abuse treatment, dental care, prescription drugs, and durable medical equipment like wheelchairs or walkers.

There are many positive aspects to New York State's Medicaid program. Consumers and providers agree that the covered benefits and services are robust. There are literally thousands of providers who accept Medicaid. As good as the Medicaid program is, however, both consumers and providers have identified issues and concerns that impact the ability to get medical care as well as to deliver medical care. Some of the key issues and concerns are summarized in the table below.

Key Issues and Concerns with NYS's Medicaid Program

1. Only one medical service per day per facility is covered by Medicaid.
2. Providers often don't talk to each other.
3. It can be difficult to get medical documentation.
4. Lots of Primary Care Providers aren't specialists in HIV/AIDS.
5. Many Specialty Care Providers that take Medicaid don't know about HIV disease and/or aren't willing to treat PWHAs.
6. It can take a long time to get specialty care appointments.
7. Medicaid co-pays and visit thresholds (or limitations) can be problematic.
8. Strict Medicaid rules for medical decisions don't take into account the full range of needs.
9. Complaints often don't get resolved.
10. Problems or issues that arise after Medicaid offices are closed (nights and weekends) must wait until the next day or Monday morning.

The New York State Department of Health AIDS Institute, advocates, and consumers have sought ways to address these issues and problems. But the reform options that are available within the regular Medicaid program are limited, and significantly impacted by philosophical changes in state and federal governments as well as economic forces.

Ps):

BY DOUG WIRTH


For more than ten years, these groups have collaborated on the development of a new health care option for people living with HIV/AIDS who have Medicaid. In 2003, that new option became a reality. This newest option is called an HIV Special Needs Plan (SNPs – pronounced “snips”). SNPs reflect an innovation in health care, maintain the full package of Medicaid benefits, and seek to strengthen the health care delivery system by addressing these persistent issues and concerns. SNPs are not just another form mainstream managed care program – they are new and unique.

Mainstream Medicaid Managed Care

The most important thing to know is that SNPs are not mainstream Medicaid managed care programs. Those programs were created to address the needs of the 4 million people who qualify for Medicaid in New York State (2.7 million in New York City). These programs don't guarantee consumers Primary Care Providers (or PCPs) with HIV expertise, nor do they contract with the full range of care models that are needed to appropriately serve PWHAs. Mainstream Medicaid managed care programs have a 9-month lock-in period, which means that you can't change programs during that timeframe.

Even though PWHAs are exempted from these programs, some PWHAs either chose to enroll, or

A Special Needs Plan, or SNP, is a comprehensive health plan for PWHAs. Being “comprehensive” means that SNPs address both medical needs and non-medical issues, like supportive services, housing, entitlements, legal concerns, and transportation.



were auto-assigned to a program. Getting out (or disenrolling) from these programs has historically been problematic for PWHAs.

The vast experiences of PWHAs in these mainstream Medicaid managed care programs were not favorable. Chief consumer complaints with the mainstream Medicaid managed care program included the following:

- 1) *PWHAs often felt they knew more about HIV disease than their Primary Care Provider (PCP) knew about HIV/AIDS;*
- 2) *It was extremely difficult to get specialty care appointments;*
- 3) *Mental health and detox services were difficult to access; and*
- 4) *Many of the HIV providers used by PWHAs weren't in the various program's provider networks.*

As a result, many medical providers and case managers worked to get their clients disenrolled from these mainstream Medicaid managed care programs. But the disenrollment process with mainstream programs, which isn't expedited, was a headache for most and a nightmare for some.

Introducing SNPs

A Special Needs Plan, or SNP, is a comprehensive health plan for PWHAs. Being "comprehensive" means that SNPs address both medical needs and non-medical issues, like supportive services, housing, entitlements, legal concerns and transportation.

SNPs offer Primary Care Providers (PCPs) who are specialists in HIV/AIDS, a broad range of medical

specialists who agree to treat PWHAs, and most important "care coordination" of all services that an individual is receiving. This means that a PWhA's care team is aware of, and informed about, all the services that a client is receiving, be it case management, detox, mental health, medications, or specialty care services.

SNPs offer state-of-the-art services through "provider networks" that include AIDS Designated Centers, HIV primary care programs, community-based HIV programs, and even private practice doctors' offices. These provider networks include virtually all the specialty services that a consumer might need. If for some reason a SNP doesn't have the service a consumer needs, they will find it and make it available to the PWhA.

PWHAs who have Medicaid, and their dependent children up to age 19 regardless of their HIV status, are eligible to join SNPs.

SNPs require that all providers maintain member confidentiality and adhere to Article 27F of the Public Health Law. SNPs work with their members to identify the best way to communicate with them while protecting their confidentiality. Some SNP members ask that health plan representatives only identify themselves as "calling from your health plan," when leaving messages. Other members provide alternative mailing addresses where all mail is sent. SNPs work with their members to address confidentiality concerns and needs.

SNPs also move away from a passive health care model where people often drop out of care to an

In SNPs, members can get as many medical services as they need, and on the same day!

assertive community treatment model where your health plan becomes your partner and advocate in ensuring that you can access all the care and services you need. SNPs will also work with you to address barriers so that you can stay in care, which includes resolving transportation issues.

And lastly, SNPs were also designed to protect the comprehensive HIV care system in New York. As more people learn that they are HIV-positive or living with AIDS, and as PWHAs continue to live fuller, longer and productive lives, the demands on the system will only increase. And as PWHAs live longer and develop additional health conditions that require treatment, such as heart disease, the care needs of PWHAs will only continue to expand. SNPs have been designed to meet all of these challenges.

SNP BENEFITS

1. *Members get all Medicaid benefits*
2. *More than one Medicaid Service per day*
3. *HIV Specialist PCP*
4. *Comprehensive network of providers*
5. *Care Team*
6. *Plan assistance available 24/7*
7. *Member Services/Care Coordination*
8. *Expedited Decision Making*
9. *Access Standards for waiting times and appointments*
10. *One Stop Shopping options*

Benefits of SNPs

PWHAs are faced with serious issues and difficult choices all the time. These challenges don't stop at 5pm. When consumers need information and assistance, they need it now, even if it's on the weekend. SNPs provide their members with assistance 24 hours a day, 7 days a week. Members can call a toll-free "1-800" or "1-866" number to get the help they need, including prompt follow-up with any concerns or problems.

PWHAs are use having to make multiple trips to their health care providers in the same week. In SNPs, members can get as many medical services as they need, and on the same day! To consumers, this says, 'We value your time. And we want to make it easy for you to get the care you need.' To providers, this says, 'We want you to offer all the care that your patients need. And we'll pay for those services, even if you deliver them on the same day.'

Living with HIV/AIDS is truly complex. There is no one right way to live with HIV/AIDS. That means that there are lots of options available to PWHAs. But who can you call to get help with exploring those options? If you are in a SNP, you can call Member Services or ask to speak to your Care Coordinator. These individuals work with you, and your providers, to make sure that:

- You know and get all the Medicaid benefits that you are entitled to;
- You can get timely appointments, or help when a provider tells you that you must wait a long time for an appointment that you need or want sooner;

cont.

cont.

- You get as many medical services as you need, and on the same day.
- Your medical providers share appropriate clinical information to advance your care;
- Your case manager gets all the medical documentation to assist you with benefits, including SSI, SSDI, or supportive housing through HASA;
- You can find a new HIV PCP when you need one, or a Specialty Care provider that is right for you; and
- You can express your concerns when you're dissatisfied, and someone will look into it and get back to you.

Accessing SNPs

In the first year of the program, 1,000 people joined a Special Needs Program. Since January 2005, another 500 people have chosen to join a SNP. Currently, there are three SNPs operating in New York City with more than 1,500 members getting services and all the other SNP benefits (see SNP Benefits chart) through these comprehensive and specialized health plans:

| Health Plan | Member Services Toll Free Number |
|---|----------------------------------|
| MetroPlus Health Plan – Partnership in Care www.metroplus.org | 1-800-303-9626 |
| New York-Presbyterian System SelectHealth www.nyp.org/selecthealth | 1-866-469-7774 |
| Vida Care info@vidacare.org | 1-800-556-0689 |

While SNPs coordinate all care and services, they don't directly provide medical services and case management. All SNPs contract with a large group of experienced providers to meet all of their member's needs.

While SNPs coordinate all care and services, they don't directly provide medical services and case management. All SNPs contract with a large group of experienced providers to meet all of their member's needs. This includes not only providers experienced in the treatment of HIV/AIDS, but also specialty providers for other care needs such as dermatology, cardiology, ophthalmology, OB/GYN, pediatrics (for your children) or neurology. These doctors and specialists, nurses, case managers, hospitals, labs and other health care facilities make up what we call their "provider network."

All SNP members have access to this comprehensive network of providers, which includes sub-specialties, hospitals, community health centers, mental health clinics, AIDS CBOs, and private doctors' offices. You can find a list of them in each SNP's published Provider Directory.



If you don't have a Provider Directory, call the SNPs toll-free Member Services department to get a copy. In addition to answering questions about which providers are in their network, SNP staff are available to help members arrange appointments and follow-up when members have questions and to answer questions from those interested in membership.


Renee Martinez, Chief Operations Officer of the Vida Care health plan, gave an example of the kinds of service offered by SNPs. "At Vida Care, one member had developed a keloid (or growth) on her face," explained Ms. Martinez. This member wanted to have it removed. Her HIV Specialist PCP wanted it removed. Medicaid Fee-for-Service considers that type of surgery to be 'cosmetic,' and therefore doesn't pay for it. But when our Medical Director looked at the situation, he agreed that not only was it a real medical need, removing the growth was a mental

health, self-esteem, and quality of life issue. And Vida Care approved the outpatient surgery to have the growth removed! That's how SNPs work with all your providers and look at the complete picture of a member's medical and non-medical needs to make informed decisions about your care."

Customer service is also at a premium. "At SelectHealth, Member Services staff are experts at helping members with their needs whether, answering questions, solving problems, navigating the network, or securing a wheelchair that has been ordered by their PCP," states Eli Camhi, Executive Director of New York-Presbyterian System SelectHealth (SelectHealth). "And we accomplish this quickly and in much less time than compared to Fee-for-Service Medicaid."

SNP provider networks include credentialed specialists in HIV care. "But living with HIV is not only about HIV care. Persons living with HIV may be at risk for heart disease, cancer or other diseases. SelectHealth's provider network includes increased access to a wide variety of specialists in HIV as well as other fields of medicine," explained Mr. Camhi. "And when you need help, our Member Services staff assist with making appointments, securing transportation and coordinating with your primary care provider."

But what if you have a problem after 5pm or on the weekends? "Many PWHAs will wait until Monday morning. Others will go to the nearest Emergency Room," stated Andrea Lieblein of MetroPlus Health Plan – Partnership in Care (MetroPlus). "And most PWHAs will have some level of anxiety or worry until they get medical care, help or answers that they need. But at MetroPlus, even on a Friday night



or over the weekend, we're available to help resolve issues and problems to make sure our members get the services that they need. And if a member has difficulty get medications on the weekend while the Medicaid office is closed, we'll work with a pharmacy and the member to resolve eligibility issues or payment problems – on the spot. This kind of customer service isn't available in the fee-for-service Medicaid program."

Are SNPs Right for Me?

Making changes – especially with health care – can be scary, is rarely easy, and often requires more information, close examination and serious thought.

An important question to ask when looking at SNPs is, "Are my providers a part of a SNP's network?" No one should ever be asked to sever a provider relationship that's working for them. So if your providers aren't in a particular SNP's network, then that SNP is probably not for you. If you don't have an HIV Specialist Primary Care Provider, or one that you're satisfied with, you can use SNP provider directories to identify potential providers.

Since there is no one right way to live with HIV/AIDS, it's important to check into health care options for yourself. If you see value and benefit in exploring SNPs, there are numerous resources to assist you in the process of getting additional information. But ultimately, the decision is yours! SNPs aren't for everyone, but they be "just right" for you!

There are a number of ways to explore SNPs further, and get the information that you need to make an informed choice. Some PWHA's want to know what their providers think, before making a choice. It's a good idea to speak to your HIV Specialist PCP about which SNPs he or she participates in. You can also find out which SNPs your HIV Specialist PCP participates in by calling New York Medicaid Choice at 1-800-505-5678.

A great way to learn more about a SNP is to call the individual health plan directly (see box above with phone numbers). Find out what special programs are being sponsored this month, or where you can go to talk directly with a plan representative about their SNP. Or, you can find out more information about SNPs by visiting the NYS Department of Health – AIDS Institute's website at www.health.state.ny.us/nysdoh/hivaids/snps/plans.htm

Doug Wirth, MSW is the former Executive Director of the People with AIDS Coalition of New York, a past chairperson of the New York AIDS Coalition, a member of the NYC HIV Planning Council, and a senior faculty member of the American Psychological Association's AIDS Hope Project. Doug is currently an independent health care consultant and maintains a private practice.

AD 2

AD 2

AD 2

Challenges When Starting Antiretroviral Treatment

Your doctor has just recommended that you start antiretroviral treatment for HIV and you are struggling with what to do. You've heard all about side effects from some of the treatments and you have heard talk about "adherence," but you're not quite sure what that means.

Despite the fact that you may have recently developed symptoms and your immune system may be deteriorating, this is not a course of treatment you should begin lightly. It's not something that simply requires that you comply with some prescribed medication regimen. To the contrary, the management of HIV therapy involves an extremely complex process, carried out by you and your health care provider.

Highly Active Antiretroviral Therapies (known as HAART) have restored many critically ill HIV-positive individuals to a level of wellness that could not have been predicted a decade ago. Unfortunately, many persons who are HIV-positive face seemingly insurmountable psychological, social and medical barriers to beginning and maintaining the rigorous treatment regimens of HAART. Overcoming these barriers takes time, and it requires knowledge.

First off, you need to understand that the regimens of antiviral treatment can have complicated

schedules along with dietary restrictions. Side effects and drug reactions are common. But once you start, you will most likely be on treatment for life.

Non-adherence to your treatment regimen – failing to take your medications on a timely basis and as directed – can lead to treatment failure, the development of resistance to the drugs that suppress your infection and increased progression of your HIV disease.

Adherence to your regimen is all-important. For other chronic diseases such as diabetes or hypertension, a level of adherence at 80 percent is generally acceptable. For HIV, however, the level of adherence required for successful suppression of the virus and improved outcomes requires that you take your medications at a near-perfect rate – 95 percent of the time or better.

Getting started

So there you are: Your health care provider tells you that you should take a combination of medications and emphasizes the importance of taking them at the right time, at the right dosage and with the right amount of food. So, what are you

feeling when you hear this news? Quite likely, you may be scared and confused about starting treatment. This is a dilemma that just about every person living with HIV/AIDS encounters at some point during their care.

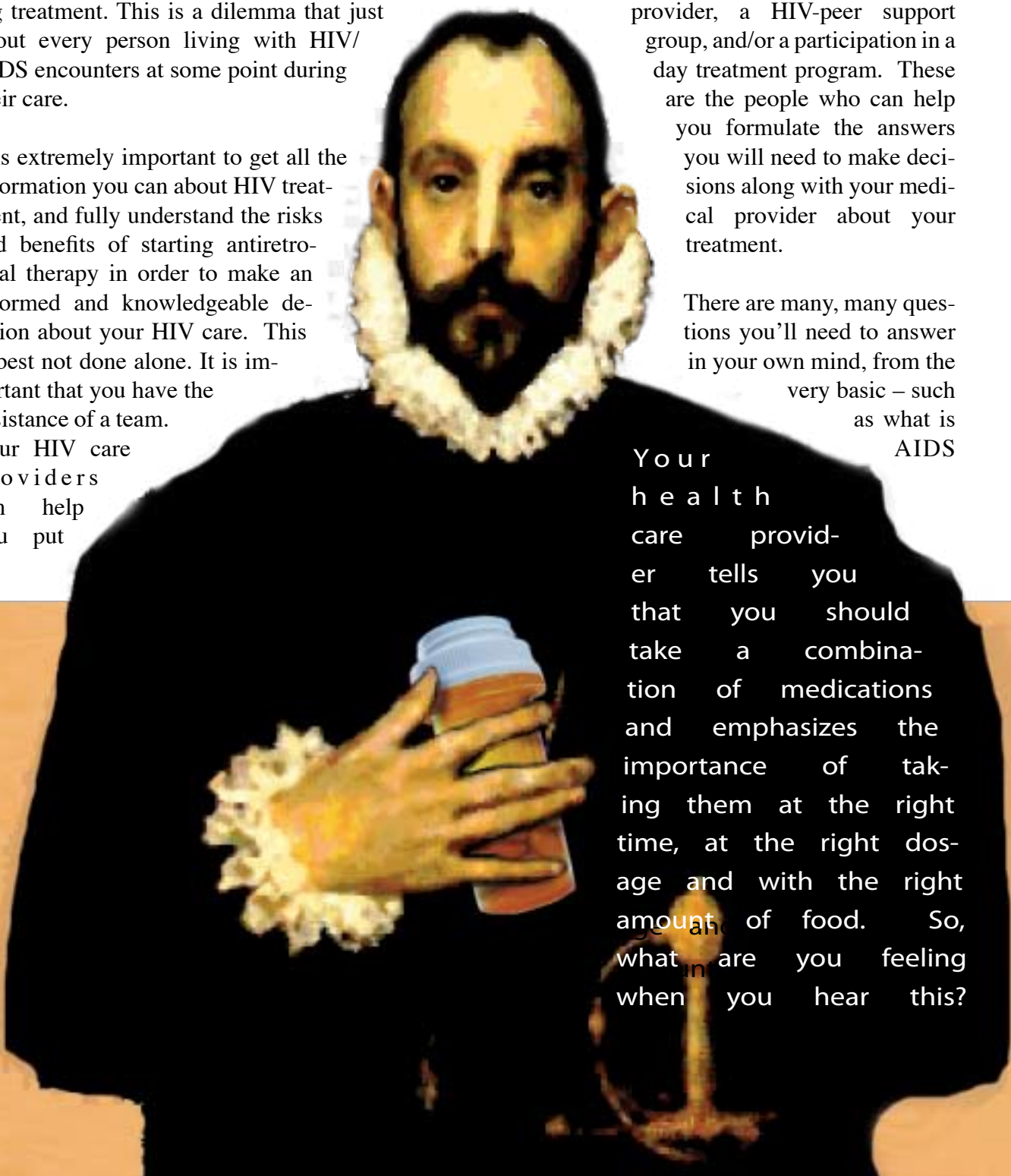
It is extremely important to get all the information you can about HIV treatment, and fully understand the risks and benefits of starting antiretroviral therapy in order to make an informed and knowledgeable decision about your HIV care. This is best not done alone. It is important that you have the assistance of a team.

Your HIV care providers can help you put

together the members of this team, which could include a health educator, a mental health provider, a HIV-peer support group, and/or a participation in a day treatment program. These are the people who can help you formulate the answers you will need to make decisions along with your medical provider about your treatment.

There are many, many questions you'll need to answer in your own mind, from the very basic – such as what is AIDS

Your health care provider tells you that you should take a combination of medications and emphasizes the importance of taking them at the right time, at the right dosage and with the right amount of food. So, what are you feeling when you hear this?



and how does HIV progress? – to more complicated ones, such as what happens if you develop resistance. Other questions might include:

- Which combination of medications should I start with?
- What options do I have if treatment fails?
- How many times during the day will I have to take medication?
- What are the food requirements and do I need a special diet?
- What side effects should I expect, how can I manage them?
- Can my HIV treatment cause other health problems?
- Will alcohol and other drugs impact my treatment?
- Will I get depressed?
- Should I get counseling?
- What will happen to my quality of life?

Those are just some of the questions you should ask and which others can help you answer.

Tips for adherence

If you've been told by your doctor that it's time for you to take antiretroviral treatment, it's a good bet that you need that treatment therapy and you need to begin as soon as possible. But you shouldn't start taking HIV medication if you are not ready. It will be difficult to stick to a regimen if you are taking your medications just because your doctor told you to take them. You need to

understand the benefit they will give you, despite the problems they may cause. Untreated, your disease will progress faster.

After you've reached a level where you understand what you are facing and you have decided with your health care provider what regimen to follow, then what? Perhaps you begin having difficulties, or you want to be prepared for the challenges of being on treatment as best you can. Below are some tips to help you improve your adherence:

Tailor your regimen. Your regimen should fit your lifestyle, your job situation and your food habits. It is more likely that you will remember to take your medications, and take them on time, when they fit into your daily routine.

Get a reminder system. There are many tools, such as pillboxes and alarms. Some people living with HIV/AIDS even have a combination of reminders. These could include tools such as a weekly pillbox, wearing a "health watch" that beeps when its time to take your medication, and keeping a medication diary to monitor dosage adherence and side effects. The medication diary entries can be of significant use to you and your health care provider in addressing treatment issues.

Keep a log to record your missed doses. This will help you assess and identify your own personal barriers to adherence. Are you missing doses because of side effects? Because you forgot?

Or were you in a situation where you didn't want to let others know your situation? A log will help you determine what's keeping you from taking your medications and how often you are missing doses. You might determine that it's something as simple as the size of the pills, or the number of pills, that bother you.

Get professional support. Just as when you went through the learning stage before starting therapy, ask your HIV-care providers for help, call HIV/AIDS hotlines, seek out HIV/AIDS resource directories and the Internet to link you with professionals who can offer your support. They will help you confront problems with adherence.

Learn about your side effects and how to manage them. Feeling sick is one of the most frequent reasons people give for stopping treatment.

Seek social support. The support of family and friends who are positively involved in your treatment can help you and be as important as a team of professionals.

Develop a partnership with your HIV primary care provider. Make sure you have a relationship with your provider that allows you to have input in decisions about your treatment.

Keep in mind that adherence is a dynamic process that varies over time among individuals and that it can, and does, fluctuate, depending on what is going on in their lives. That is why you need to be ever-vigilant in your medication management



in your battle against the barriers to adherence, which may change over time.

Beyond the mental health, attitudinal and behavioral issues that traditionally affect adherence to medical treatments, there are other barriers that need to be addressed. These include lack of knowledge and understanding of the effectiveness of treatment and the importance of medication schedules. The way you feel about your HIV disease could also be a barrier to adherence.

You should make sure to know the nutritional requirements of your treatment and the impact of side effects and be sure to acquire adherence tools. And get others involved in your treatment -- friends, family and professionals who can help you maintain your regimen, who can be there when things get difficult and on whom you can rely for support and information.

Laurie Newman M.A., M.P.H., a senior research scientist, is the director of Village Care of New York's Treatment Adherence Program. Carmen Rodriguez, is a health educator supervisor for the Treatment Adherence Program and a staff member of the Village Care Research Department. Village Care offers treatment adherence services at its AIDS day treatment programs in Manhattan and can be reached at www.vcny.org or 212-337-5600.

A Comprehensive Treatment Approach to HIV

During the past decade, the treatment of HIV has evolved in many ways. We now have over 25 drugs with which to treat this infection. Laboratory testing includes “ultra” sensitive viral load tests and phenotype resistance evaluations. And the frequency of taking antiviral medication, in many cases, is down to a few pills just once per day. Many of us present at the beginning of the epidemic only dreamed these advances might someday come true.

While there has clearly been remarkable progress, significant problems still exist. Two important questions include:

- 1) How can the progressive toxicity these medications often cause be lessened?
- 2) How can I make sure that the antiviral medications I am taking remain effective for as long as possible?

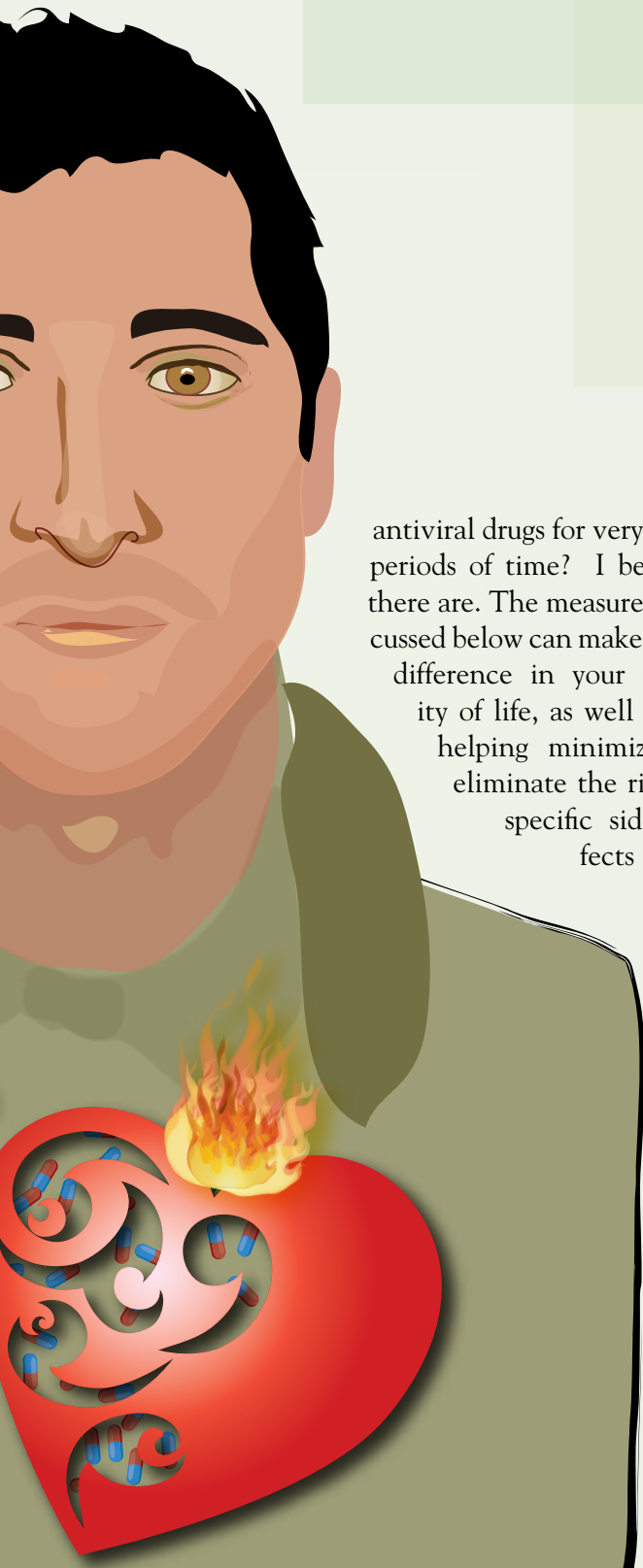
First, there is unquestionable evidence that the longer a person takes antiviral medication without interruption, the greater the risk of developing significant side effects. These can include heart disease, liver problems, body fat changes, lipid abnormalities, nerve pain, and insulin resistance. Therefore, the current practice of using continu-

ous antiviral therapy as the sole way we treat this condition leaves much to be desired.

Reducing Toxicity

So, are there ways to lessen the cumulative toxicity that comes with taking

...if you are taking HIV medications and continuing to smoke you are more than doubling any increase in heart attack risk from your meds alone...



BY JON KAISER

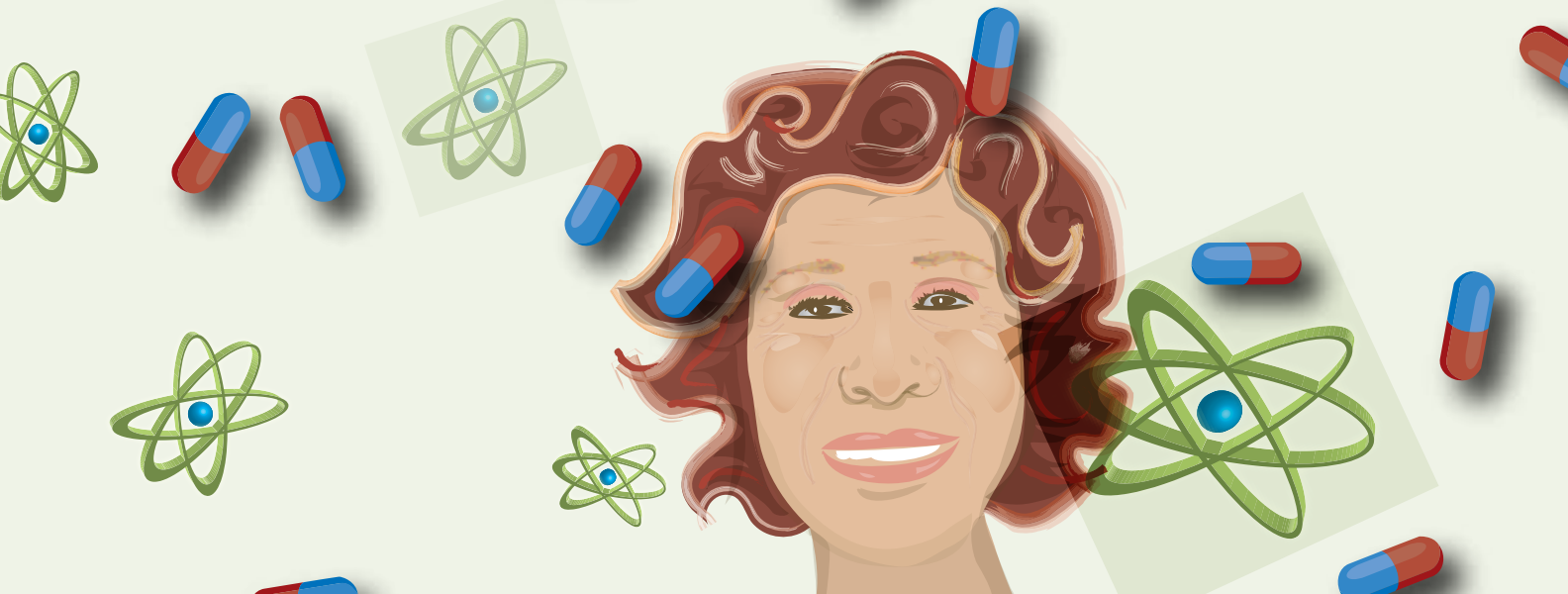
antiviral drugs for very long periods of time? I believe there are. The measures discussed below can make a big difference in your quality of life, as well as in helping minimize or eliminate the risk of specific side effects that

many people experience when they take antiviral medication.

Heart Disease: While studies have shown that the risk of having a heart attack or stroke increases the longer a person takes antiviral meds, these studies also show that smoking and poorly controlled high blood pressure pose a far greater risk. Therefore, if you are taking HIV medications and continuing to smoke you are more than doubling any increase in heart attack risk from your meds alone. Of course, eating a low fat diet, keeping your cholesterol level well-managed, and exercising regularly can also decrease your risk of cardiovascular-related side effects.

The key point is this: using natural therapies such as a healthy diet, regular exercise, and smoking cessation can make a big difference in whether or not you experience cardiovascular disease as an antiviral-related side effect. This is one example of how utilizing a combination of natural and standard medical therapies can give you the best possible results.

Lipodystrophy: Another example of how using natural therapies can help minimize antiviral drug side effects is in the case of the abnormal body fat



changes called lipodystrophy. Body fat changes often occur due to a number of factors that can be identified and addressed. These factors include a high triglyceride level, a low testosterone level, and a sedentary lifestyle. When these three factors are combined, there is an increased risk of lipodystrophy, particularly an accumulation of fat in your belly or neck. In order to address or prevent lipodystrophy, make sure that you are eating a low-fat, low-sugar diet, that your testosterone level is in the upper part of the normal range (usually between 500-1000), and that you are getting regular exercise (at least two or three times per week).

At this moment in time, very few of my patients who follow the above guidelines have experienced lipodystrophy. In addition, this set of recommendations will also offer protection against diabetes, heart disease, and a loss of your muscle mass. Using natural therapies such as a healthy diet, hormone supplementation, and regular exercise can make a big difference in whether or not you experience lipodystrophy as an antiviral-related side effect.

Intestinal Health: Some of the most common complaints among people with HIV include intestinal symptoms such as gas, bloating, and diarrhea. Many people (and docs as well) believe these symptoms are just a part of living with HIV, but I do not!

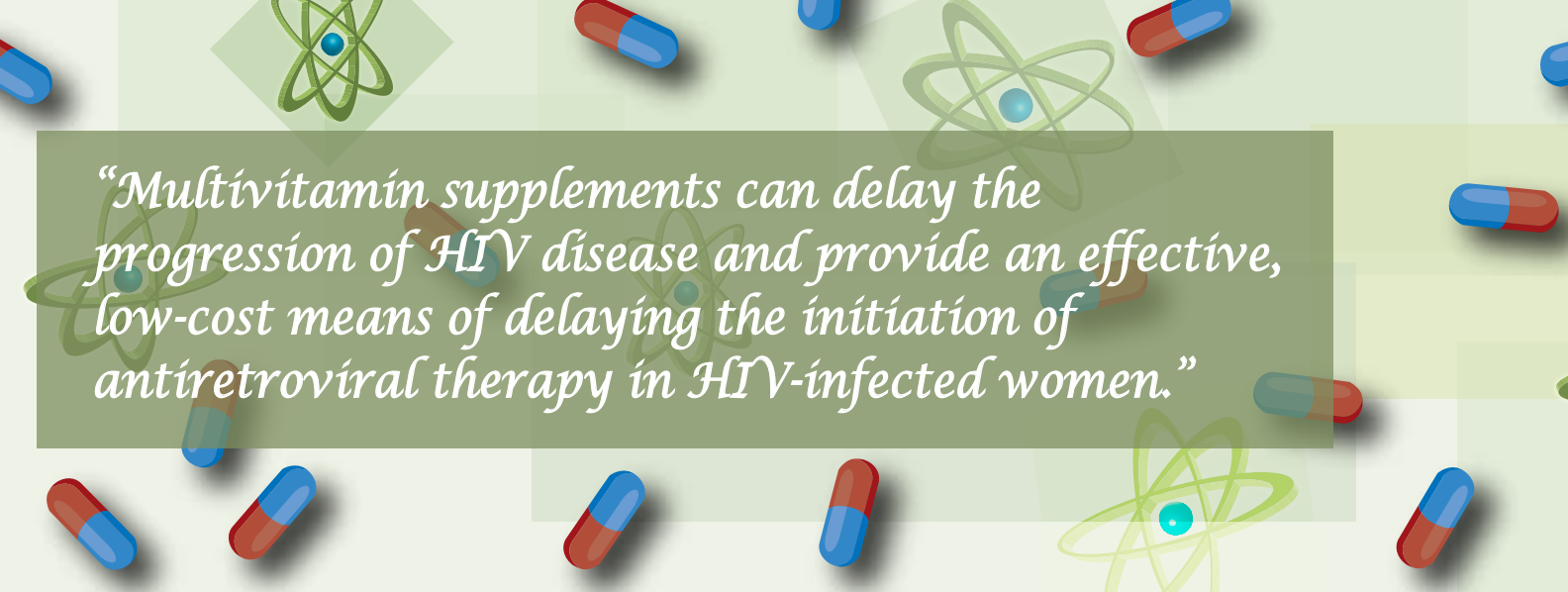
Gas, bloating, and diarrhea are symptoms that are often ignored or just treated symptomatically with meds such as Imodium or Lomotil. This is unfor-

tunate because these symptoms are usually caused by a combination of unhealthy bugs in the gut (intestinal parasites), low levels of healthy intestinal bacteria (acidophilus and bifidus), and poor dietary choices (too much grease and sugar). By cleaning up your diet (i.e. eating less fat and sugar as well as more fruits, grains and veggies), taking a daily probiotic supplement to boost acidophilus levels, and experimenting with digestive enzymes to help boost your digestive juices (available in pharmacies and health food stores), most intestinal symptoms can be eliminated. This approach can also improve your quality of life and help you tolerate your meds much better.

I recommend that everyone who is HIV-positive get screened for intestinal parasites once a year. In my experience, 30% to 50% of people with HIV are presently walking around with parasites and don't know it. These bugs in your gut affect your digestion, inhibit the proper absorption of nutrients, and place increased stress on your immune system (causing unwanted immune activation).

Including Micronutrients

The daily intake of a micronutrient supplement (that includes vitamins, minerals, and antioxidants) can also provide a beneficial support to the immune system. One of the most important of these supports is to help every cell of your body effectively neutralize free radicals. These are the toxic byproducts of normal energy production that



“Multivitamin supplements can delay the progression of HIV disease and provide an effective, low-cost means of delaying the initiation of antiretroviral therapy in HIV-infected women.”

have been shown to be at higher than normal levels in the cells of people with HIV whether they are taking antiviral medication or not. By properly supporting the micronutrient needs of your cells, conditions such as neuropathy, lipodystrophy, heart disease, liver failure, and CD4 cell decline can possibly be prevented.

There is sound research to support the use of a micronutrient supplement as part of a comprehensive treatment of HIV. A recent study published in the New England Journal of Medicine (NEJM) in July 2004 stated: “Multivitamin supplements can delay the progression of HIV disease and provide an effective, low-cost means of delaying the initiation of antiretroviral therapy in HIV-infected women.” A second study published in AIDS, the journal of the International AIDS Society, found that, “Administering a micronutrient supplement to HIV-infected men and women living in Thailand decreased HIV-associated mortality by 50% compared to the placebo arm.”

I have also recently completed a double-blinded, placebo-controlled research trial in 40 people with HIV in the United States who were taking antiviral medication. This study was funded by the Bristol-Myers Squibb company. The study found that a micronutrient supplement could increase the CD4 count in people with HIV on antiviral medication by an average of 26% compared to no change in the placebo group. This study is currently under review for publication in a peer-reviewed journal.

It is my goal to perform further high quality research on this topic, and if micronutrient therapy continues to show significant benefit to people with HIV, to see that it is covered by insurance and government programs (i.e. Medicaid). The micronutrient supplement that was used in this study is now available under the brand name “K-PAX” and is presently covered by the NY State ADAP program with a prescription from your doctor.

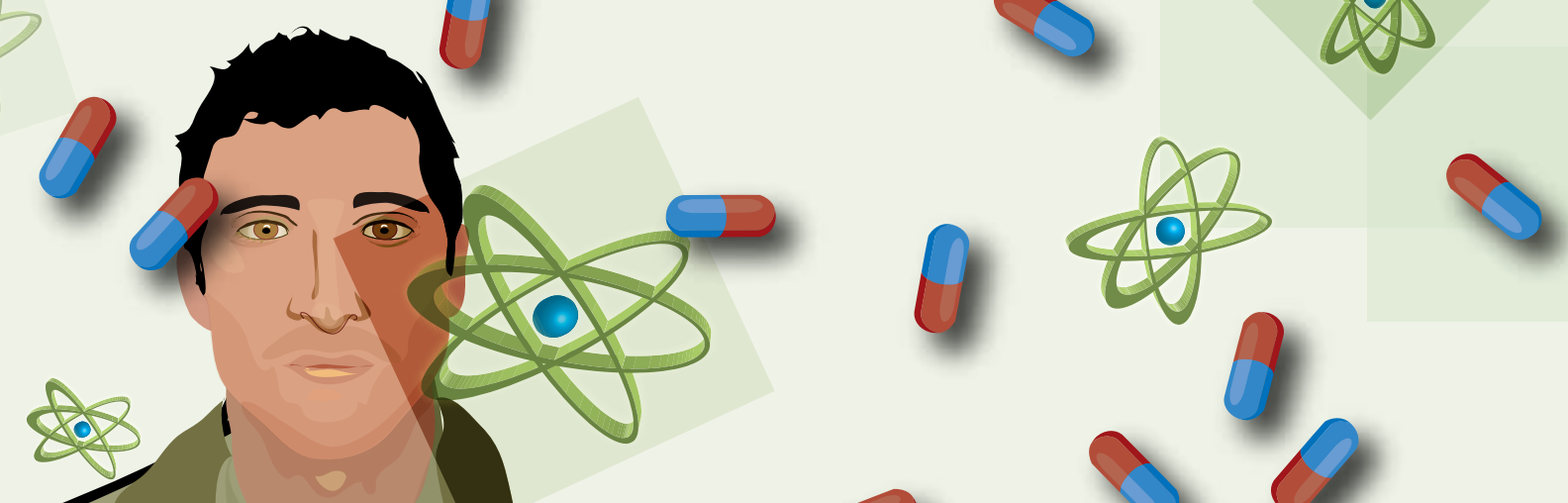
Maintaining Effectiveness

The second question I posed at the beginning of this article was, “How can I make sure that the antiviral medications I am taking remain effective for as long as possible?”

The answer to this question includes the following four points:

- 1) Don't miss doses of your meds
- 2) Take the best possible care of your body
- 3) Take a high potency daily micronutrient supplement
- 4) Get tested for intestinal parasites and get rid of them if they are found

Don't miss doses of your meds: There have been many well done clinical trials that show a very strong correlation between missed doses of meds and the development of antiviral resistance. Anything less than taking 90% of your medication doses will likely shorten the length of time that the drugs you are taking will work.



Why is this a big problem? If your drugs wear out prematurely, you will go through the available list of drugs too fast and there will then be none left to use. However, if you always have effective treatment options available to use to treat this infection, you will most likely live the longest lifespan possible.

Take the best possible care of your body: This means not abusing your body by regularly consuming alcohol, cigarettes, crystal meth, and other recreational drugs that are proven toxins. If you want your body to stay healthy and treat you right, you've got to treat it right too!

Next, try to eat as healthfully as possible. As I stated before, the best diet to consume is one that includes plentiful fruits, grains and vegetables, as well as a minimum of fat and sugar. Also try to make sure that you get a good amount of protein at every meal. These are proven ways to help keep your immune system strong.

Regular exercise should include a mixture of weight training and cardiovascular activity two to three times per week. Even if you can't get to a gym to exercise, taking a daily walk, using the stairs instead of the escalator, and trying to do some push ups, sit ups and stretching on a regular basis can really help keep your body fit.

Take a high potency daily micronutrient supplement: As I discussed above, there is an increasing body of research that suggests a potent micronutrient supplement, taken on a daily basis, can help delay the need to start antiviral medication as well as

provide a boost to your CD4 count if you have already started taking the meds. There is also sound evidence that shows a potential for antioxidants to lessen the risk of antiviral drug side effects. Do some research on the web or talk to your doctor or pharmacist to identify the micronutrient supplement that fits your needs and budget the best.

Get tested (and treated) for intestinal parasites:

In my opinion, this is just as important as any of the above items. Many people harbor these bugs in their gut and don't know it. The only way to find out for sure is to ask your doctor to order a test called an "O&P times three." It requires collecting a sample from three separate bowel movements and then taking all three to the lab. For a complete review of the diagnosis and treatment of intestinal parasites visit www.jonkaiser.com.

In summary, I now hope you can see the important benefits that can be achieved by combining natural therapies with standard therapies in the treatment of HIV. If the above recommendations are taken to heart it is my belief that most people with HIV have the potential to live a normal, healthy lifespan. This is what I set as the goal my patients and during the past ten years of watching them follow my treatment guidelines, I see no reason to believe otherwise. I hope some of this information helps you to achieve the same!

c. 2005 Jon Kaiser, M.D.

Jon Kaiser, M.D. has been caring for people with HIV and other immune system disorders in San Francisco for the past fifteen years. The latest information on his treatment guidelines, as well as access to his quarterly



NewYork-Presbyterian System

Select Health

SelectHealth is a Medicaid Special Needs Plan (SNP) designed specially for people living with HIV and their children. If you qualify and live in the Bronx, Manhattan or Brooklyn, you can choose to join SelectHealth — give us a call.

(1-866-469-7774 toll free)

www.nyp.org/selecthealth

To learn more about HIV SNPs, call the New York Medicaid CHOICE Helpline at 1-800-505-5678.

SPONSORED BY

**NewYork-Presbyterian
Healthcare System**

MetroPlus' Partnership in Care is a
Medicaid Special Needs Plan for people
living with HIV/AIDS and their children.

MetroPlus
Health Plan

 MetroPlus
Health Plan
www.metroplus.org

 You can call New York Medicaid CHOICE at
1-(800)-505-5678 for more information.

WWW.METROPLUS.ORG Call **1-800-475-METRO**

Factors Influencing Adherence

Non-adherence of antiretroviral therapy can lead to higher viral loads and viral resistance, while proper adherence is linked with viral suppression. Data show that adherence of over 95 percent is needed for effective viral suppression. Adherence to anti-HIV medications is critical because of the increased chance of developing drug resistance and, according to the U.S. Department of Health and Human Services (DHHS) HIV/AIDS Bureau, “a treatment’s success can begin to diminish when patients are less than 95 percent compliant.”

Recently Richard Day Research conducted a study underwritten by Bristol-Myers Squibb of 403 HIV-infected persons taking antiretroviral therapy on average for eight years and who had switched regimens four times. A number of important findings are identified below.

As this survey defined adherence in terms of doses missed or taken late, the results showed only 48 percent were considered adherent. Breaking medication habits down further, based solely on the number of doses missed during the past seven days, 69 percent were considered adherent (defined as taking 95 percent or more of all required doses), while 31 percent were not. Sixty-six percent said they were fully adherent in that they had not missed a single dose in the past week, while 17 percent reported missing a single dose and another 17 percent reported missing two or more doses within the past seven days.

According to survey participants, the primary reason for becoming less adherent (cited by 29 percent in open-ended format) is due to being busy with

work or life demands. More than one-third (38 percent) reported that although they “strongly” or “somewhat agree” that they want to take their medications, they sometimes forget or fall asleep. Twenty-two percent said forgetting to carry their medications with them when they were away from home was a problem. Psychological and personal control issues are important barriers for some patients, who do not yet feel they are fighting HIV on their own terms; these individuals continue to be challenged by side effects and by disruptions to their daily routines and eating habits. Consistently, one-quarter to one-third of respondents felt they are not yet controlling how HIV affects their lives: thirty-three percent reported they have had to tailor their life to their HIV treatment regimen, 24 percent agreed that “HIV is controlling me, instead of me controlling it” and 37 percent said having to take HIV medications means having less freedom. Twenty-seven percent felt having to take HIV medications was embarrassing.

While 87 percent felt a strong commitment to taking their antiretrovirals as prescribed, side effects (47 percent), feeling ill (21 percent), or being depressed (23 percent) were the most frequently cited reasons offered for why adherence can be difficult. They reported that the following side effects had the greatest influence on adherence: fatigue (42 percent), diarrhea (40 percent), nausea (29 percent), problems with sleep (28 percent), depression (26 percent), and body shape changes (26 percent). In addition, 34 percent cited concerns about the long-term effects of HIV medications as a reason taking HIV medications can sometimes be difficult. Although cited less often than side



Patients said taking personal responsibility for their own success was essential, and recommended strategies to keep dosing easy and pills accessible.

effects, other barriers to adherence included too many pills to take at one time (23 percent), difficulty coordinating medications with daily schedule, changing schedule, or with their job (19 percent), pills too large and hard to swallow (19 percent), or difficulties when medications need to be taken with food (19 percent). However, it is noteworthy that the frequency of dosing was cited as a major barrier by only 11 percent. In open-ended format, “being too busy” and “forgetting” was the top reason cited by 46 percent of those providing open end answers as the reason for missed or late doses within the past seven days.

Sixty-two percent have been able to tailor an antiretroviral regimen that suits their lifestyle. Patients said taking personal responsibility for their own success was essential, and recommended strategies to keep dosing easy and pills accessible. Ninety-three percent declared they themselves had the strongest influence on their success with adherence; 22 percent cited the influence of their health care providers, and 20 percent relied on immediate family members and partners. The most effective adherence strategies were ranked and the ones most frequently cited were using a pill container (48 percent), keeping pills in an obvious place (42 percent), switching to simpler regimens with lower pill burdens (40 percent), linking dosing to specific

aspects of their daily routines (37 percent), working with their provider to tailor a regimen that suits their daily schedule and lifestyle (20 percent) and switching to a regimen with more tolerable side effects (30 percent).

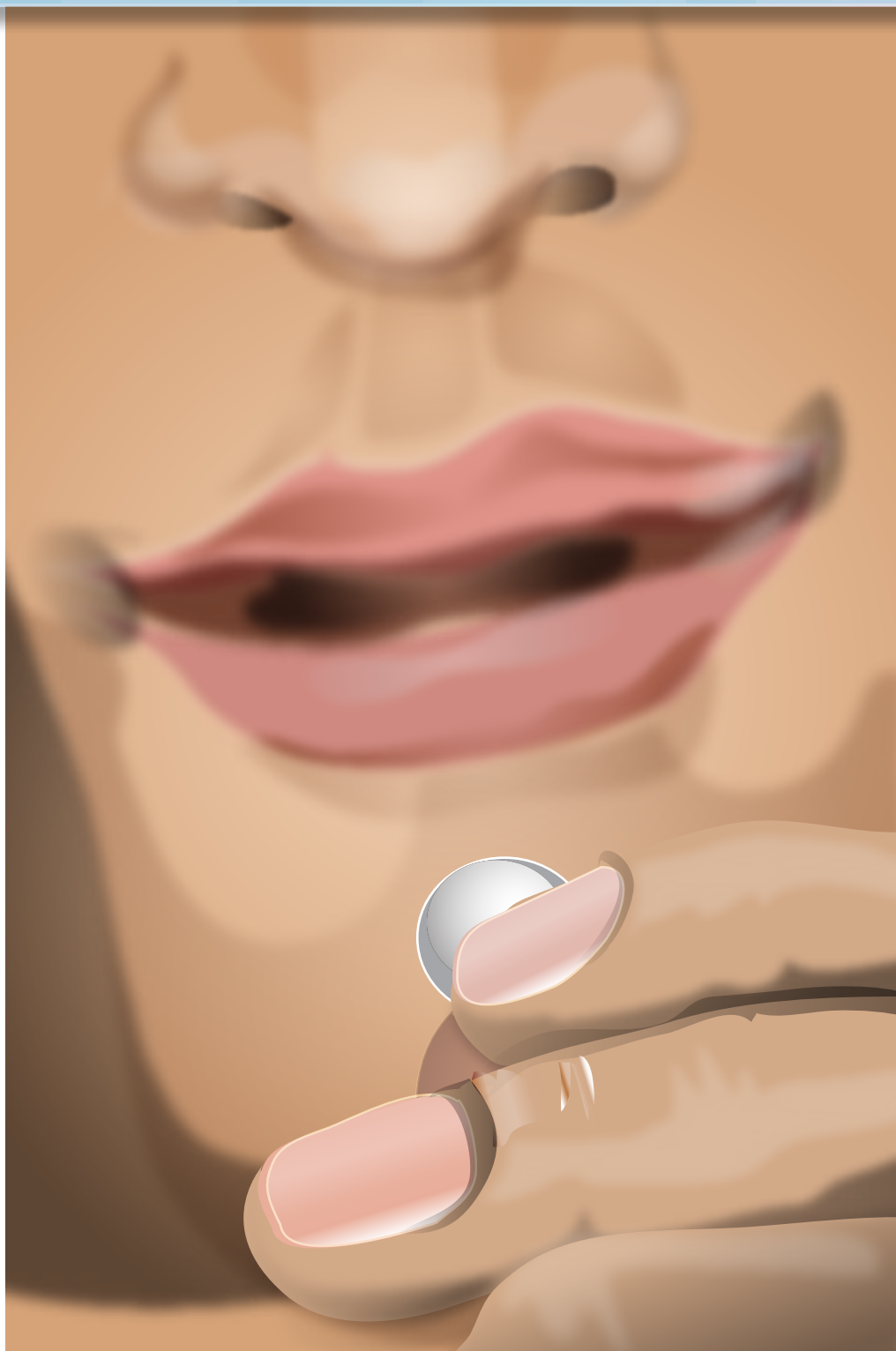
There are a number of benefits to complete adherence, such as better HIV suppression and limiting the emergence of resistance. This survey showed that other important benefits are the improved sense of control over patients’ lives reported by 62 percent, worrying less about having HIV (44 percent), feeling healthier (43 percent) and possessing a sense of well-being (41 percent).

However, nearly one quarter (22 percent) did not believe their healthcare providers really understood how hard it is for them to take their antiretrovirals. Twenty-six percent said they had not been given a choice of treatment regimens that suits their lives best. According to the DHHS Guidelines, health-care providers can and should adjust regimens to suit a patient’s lifestyle and address other issues such as side effects. When this is done, the chance of adherence success has been found to increase.

This survey was designed by Richard Day Research of Evanston, IL and edited by Dr. Judith Feinberg, professor of medicine at the University of Cincinnati College of Medicine and principal investigator at the University of Cincinnati AIDS Clinical Trials Unit. It was conducted online in June, 2005 by Richard Day Research. This educational initiative is underwritten by Bristol-Myers Squibb.

BY GARY R. McCLAIN

It's Not Only About the Pills



If You're Changing to a New Regimen, Don't Neglect Your Emotions

“It looks like I’m going to be starting a new drug regimen.”

As a counselor, I often find myself sitting across from a client who begins the conversation with these words. Each has his or her own reasons for changing regimens, including efficacy, side effects and compliance issues.

If you are facing a change in your regimen, or have been presented with this possibility by your physician and are talking about the next steps, chances are you are experiencing your own thoughts and emotions. What I have learned from my clients is that a new drug regimen presents both challenges and opportunities. And like other life changes, the best way to tackle them is through acknowledging our emotions, harnessing the power of your rational mind, and taking action.

Are you ready to get started?

Remember that you are not at square one. In the immortal words of Joan Crawford in the film *Mommie Dearest*: , “This ain’t my first time at the rodeo.”

As you approach your regimen change, don’t forget that you have been down this path before. Whether this is the first time, or if you have changed too many times to count, or at least feel that way, you are not a stranger to facing the uncertainties of putting new medications into your body. You’ve been through whatever period of time it takes your body to adjust, the temporary and potentially long term side effects, and the frequent monitoring.

So you’ve got an edge here. I have clients who, because of past experiences, approach their regimen with bravado – a “dare you to defeat me” attitude and a lot of chest pounding. This attitude may result from having worked closely with their physicians to evaluate potential regimens and to determine when to begin the new therapy, with confidence that they have chosen the optimal route. Enthusiasm may also be related to an intense sense of relief due to the end of regimen that has been difficult to maintain, or has resulted in intolerable side effects, or has become less effective. But is there another side to the bravado?

Some clients use their bravado as a way of avoiding some of the less acceptable, uncomfortable feelings that a new regimen may provoke – anger, fear, frustration – while others don’t even attempt to hold back on the dark side but instead go there and stay. They recall past experiences with new regimens that caused intestinal distress, or nightmares, or fatigue. If they had to face it in the past, how could this one be any better? They can’t help but wonder: what next?

Are your coping skills rusty?

Let me tell you about a client who I will call Doug, who has been HIV positive for 15 years. As a veteran of AZT, he is no stranger to changes in his medication. He has gone through a few of them over the years. He has been on his current regimen for more than two years but has gradually become resistant to it, so he finally agreed with his physician that it was time to change. But that doesn’t mean Doug was looking forward to this change.

I had my treatment down to a routine. I was calling my meds my vitamins. Now, that's a joke. I mean I wasn't even thinking about them any more and was barely aware that I was popping them at the same times every day. It's like they were just pills that had nothing to do with HIV.

Doug was overwhelmed by the idea of having to make changes in his routine to accommodate the new regimen, along with the adjustment that his body would have to go through. But more important, he didn't want to face the feelings that went along with this change. With a comfortable medication routine, HIV stayed in the background. With a regimen change, he was going to need to be conscious of how he was feeling physically and emotionally from the perspective of his HIV. He was going to have to adjust his schedule to accommodate his regimen. Basically, the prospect of paying more attention to his medications made Doug feel like a patient and disempowered. He thought he had long ago left the patient label behind and wondered how much old territory he was going to have to cover again.

You may want to ask yourself the question I asked Doug: **What worked and didn't work the last time you went through this?**

Take a moment and think about past experiences with regimen changes, or even back to when you first began taking HIV meds. What helped you to handle the emotions you were experiencing around this new chapter in your life? Did you get informed? Connect with supportive people? Make lifestyle changes? Get in touch with your spiritual side? In other words, how did you get to the other side of what may have seemed like a very deep valley? Just as important, what did you do that didn't help at all? What bumps in the road could have been avoided?

If you take a look back, you may rediscover some coping mechanisms that have slackened off due to lack of use but, with some exercise, can again be relied on to help you deal with this challenge. Below are some ideas you may find useful.

Update Your Knowledge: I often hear that, over time, people's drive to actively gather information has declined when the current medication is doing its job or they've grown to trust their doctors. How long has it been since you updated your knowledge about HIV and the latest treatments? Some clients approach their new regimen with such enthusiasm that they don't want to "jinx" anything by over-analyzing or otherwise questioning the limitations and the benefits of the new regimen. Others avoid knowing too much out of a concern that their worst expectations will only be confirmed. Either way, a new regimen is often the kick in the butt that gets people re-involved in their treatment. Is it time for you to start asking questions again and seeking answers? The HIV medication picture is constantly changing. If you haven't been keeping yourself educated, or have gotten out of the habit, now could be a good time to restart the process. Even a few minutes a week, on a regular basis, can be a step toward staying informed and can give you an outlet for the anxiety and frustration you may be experiencing.

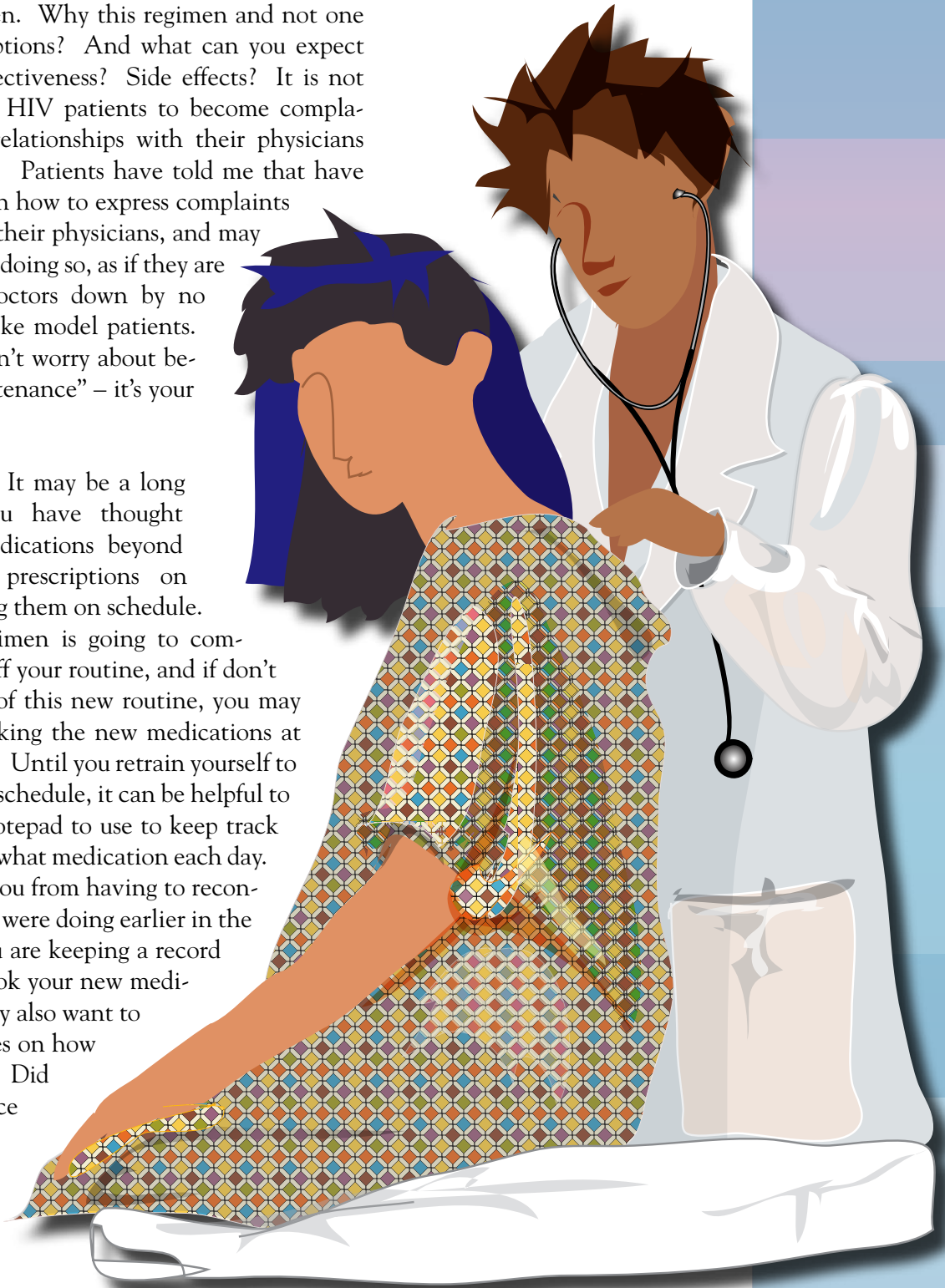
Don't Hesitate to be High Maintenance: Getting involved begins with asking questions. If you haven't asked why a regimen change is recommended, that would be the starting point. While the answer may be obvious to you (for example, if the side effects were becoming intolerable) your physician may still be able to give you additional insights into why the regimen is being changed at this time. What are the risks of changing the regimen in terms of keeping the virus in check? And then there is a whole new set of questions regarding

It is not uncommon for HIV patients to become complacent in their relationships with their physicians over the years.

the new regimen. Why this regimen and not one of the other options? And what can you expect in terms of effectiveness? Side effects? It is not uncommon for HIV patients to become complacent in their relationships with their physicians over the years. Patients have told me that have almost forgotten how to express complaints or concerns to their physicians, and may even feel guilty doing so, as if they are letting their doctors down by no longer acting like model patients. But you shouldn't worry about being "high maintenance" – it's your health at stake.

Keep Records: It may be a long time since you have thought about your medications beyond keeping your prescriptions on hand and taking them on schedule.

But a new regimen is going to completely throw off your routine, and if don't stay conscious of this new routine, you may find yourself taking the new medications at the wrong time. Until you retrain yourself to follow the new schedule, it can be helpful to carry a small notepad to use to keep track when you took what medication each day. This will save you from having to reconstruct what you were doing earlier in the day. While you are keeping a record of when you took your new medications, you may also want to make brief notes on how you are feeling. Did you experience some nausea one afternoon? Write it down.

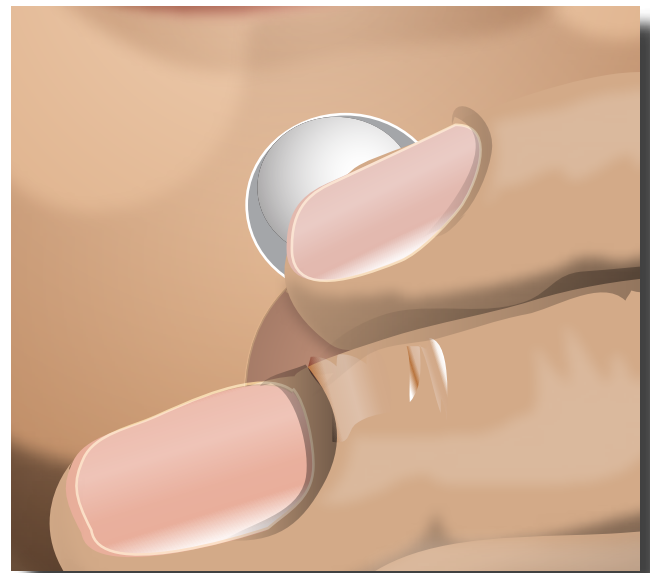


Find a safe place to talk and strategize with someone who cares about you and understands what you are going through.

Dizziness or a headache on another day? Make a note of that too. And what about questions? It can be helpful to keep track of your questions in this same notepad, which you can bring to your next doctor's appointment.

Stay Connected: Because a new regimen can raise some unfamiliar issues and emotions, it can be really helpful to have a place to talk about what you are going through. You may want to connect with a support group through a community center or HIV organization. Here, you are likely to find people who are going through the same situation as you are, and possibly with the same regimen, who can offer both emotional support and their own perspectives. If you are involved in a church, or synagogue, or a spiritual group, this may be a time when you want to reach out for support. You may also want to consider talking to a counselor who is experienced in dealing with HIV-related concerns. This is not a time to be alone. Find a safe place to talk and strategize with someone who cares about you, understands what you are going through, and who can also be an objective sounding board.

Adhering to Your Regimen: Depending on what you were facing with your most recent regimen, adherence may have become an issue. Consequently, you may be looking forward to an easier schedule with the new regimen, or have other reasons for anticipating the change. Or, as I discussed earlier, the new regimen may look like a steep uphill climb. Either way, you don't need another lecture about adherence. But if you have doubts about your ability or willingness to stay with it, talk to your physician so that he or she can explore whether the



regimen is having a biochemical effect on your mood. Talking about your emotions with a support group, friends, or a professional counselor can also be helpful.

A new regimen can unleash a whole range of emotions, some of them a blast from the past, and some of them brand new, and your emotions can impact effectiveness of the new regimen as well as adherence. This is not the time to continue going it alone. Keep a close watch on how you are feeling emotionally, and don't hesitate to ask someone else to watch with you.

Gary McClain, PhD, is a counselor in New York City. He is developing a Website, www.IJustGotDiagnosed.com.



**Agouron Pharmaceuticals
Bristol-Myers Squibb
Chiron Corporation
Dupont Pharmaceuticals
Glaxo/Smithkline
Merck & Company
Roche Laboratories
Vertex Pharmaceuticals**



All these major companies trust HX magazine to deliver their messages. Shouldn't you?

Call Gary Lacinski at 212.352.3535 x12
or email: glacinski@hx.com

"HX has had a tremendous effect on our ability to recruit a diverse group of gay men for our research studies"—Michael Camacho, Recruitment Coordinator from Project Achieve

"The indispensable guide to all things gay."—*Details* magazine

Maximizing Medication Benefits with

Natural Therapies

BY JOANN YANEZ

Antiretroviral therapy has changed the face of HIV over the last decade and a half. Patient life expectancy has increased tremendously and we no longer associate many of the opportunistic infections as early-onset symptoms. Drug regimen pill burdens have also decreased for most, making adherence to protocols easier as well.

When changing protocols or adding in new therapies, however, sometimes side effects can interfere with quality of life and the likelihood that a patient will want to maintain the therapy. I have worked for almost 10 years with HIV-positive patients and have seen first hand how natural therapies dramatically help manage side effects of medications, improve quality of life, protect the body from the chemical processing of the medications, and possibly prevent 'drug failure'. The following is a review of natural therapies for optimizing the benefits of antiretroviral drug treatment.

Immune Stimulation

The immune system helps us navigate safely in our environment and avoid over- and under-reacting to foreign substances. My first suggestion to boost immune function in people living with HIV is to identify and treat underlying food and environmental sensitivities and limit immune taxing behaviors. Stress and sugar consumption have been clinically shown to depress immune function. This is exactly what we don't want to have happen in people living with HIV. Many relaxation techniques exist to help us cope with life

issues and lessen the physiological response in the body; yoga, meditation, exercise, support groups, counseling and prayer can all be helpful. Local resources exist to help you find the closest and best group for you. In the meantime, for a quick "stress break," I recommend the 4/8 Time-out. It's easy to do, free and can help diffuse a stressful moment in about a minute.

4/8 Time-out

- 1) Start by closing your eyes and focusing on your breath.
- 2) Inhale deeply through your nose for a count of four.
- 3) Exhale fully through your mouth for a count of eight.
- 4) Repeat until the stressful feeling passes, usually 3-4 cycles.

This technique can be modified for pain management. When inhaling, picture healing energy entering the nose; when exhaling, picture the pain and negativity releasing from the body and leaving.

Limiting sugar consumption to unrefined, natural forms and eating whole foods helps to improve immune function and promote a healthy gastrointestinal tract. Natural sugars exist in fruits and vegetables, honey (avoid unpasteurized), rice syrup and other sources. A non-caloric natural sweetener is the herb Stevia. It has a natural sweet flavor without artificial additives or calories.

Herbs and Nutrients for Immune Stimulation

Astragalus is a Chinese herb that has been used for centuries for its immuno-modulating qualities. There is mixed scientific evidence on its efficacy with HIV, but well documented studies on its ability to stimulate the immune system. Many patients use this synergistically with other immune boosters such as reishi, maitake and shitake mushrooms.

Glycyrrhiza (Licorice) also has been used as a complementary immune modulator, although it should be avoided in people with hypertension. In my experience the immune modulators work much better when combined together rather than used as singular treatments. Licorice can be consumed as a tea daily and the mushrooms may be included in food preparation or taken in liquid tincture form for a more consistent higher dose.

Boxwood has been shown in research to foster immune stimulation and promotion of t-cell activation. This can be found in capsule form and taken as directed by a healthcare professional.

Echinacea has been documented to stimulate the chemicals that promote t-cell activation and antibody production. It is very effective in lessening the course of the common cold and respiratory infections when used short term. There are some conflicting studies on its use long term as well as a caution that it may briefly increase viral load. Clinically, I have no problem in its short-term use for respiratory infections – but avoid long term use as well as use prior to viral load blood counts. During the acute onset of a cold, 2 to 4 cups of strong echinacea tea or 3 capsules 3 times daily can help limit the course of the illness.

Pau D'arco and Una de Gato (Cat's Claw) are also clinically used to stimulate immune function and may be consumed in tea form daily or liquid tincture either during acute illness or as a preventative measure.

Protecting Against Free-Radical Damage

As I sit in my New York apartment writing this article, free radical damage is occurring! This is part of the natural progression of aging, breathing and living but also can get sped up as a result of many medications and lifestyle choices. Free radicals are chemicals present in the body that increase the rate of cellular and tissue damage. Smoking, drug and alcohol use contribute to this as well as contact with environmental chemicals, pesticides and food additives.

For this reason I suggest water filtration, a diet rich in whole, unprocessed foods, and purchasing organic products whenever possible. There are naturally occurring antioxidants present in fresh fruits and vegetables, such as berries, citrus, tomato and peppers. These are best consumed fresh or frozen, as much nutrition is lost in the canning process. A healthy diet and lifestyle with inclusion of some of the following nutrients will help guard against the inevitable damage of free-radicals and may slow progression of tissue damage. Dosages depend on patient health status and existing conditions.

Herbs and Nutrients to Protect Against Free-Radical Damage

Alpha Lipoic Acid targets liver protection and is helpful for patients on hepatotoxic medications such as antiretrovirals, antifungals and typically any long-term medication protocols. No known contraindications exist.

Beta-carotene is helpful for optimal eye health and the water soluble form of Vitamin A is found in most multivitamins.

Coenzyme Q-10, the major antioxidant in cardiac tissue, also has protective effects on brain tissue. Studies indicate high dosage can be used safely and effectively. Certain cholesterol lowering drugs have also been shown to deplete coenzyme Q-10. Patients on cholesterol lowering drugs should

Natural therapies dramatically help manage side effects of medications, improve quality of life, and protect the body.

Natural Therapies

consider adding at least 200mg of CoQ-10 daily.

N-Acetyl Cysteine (N-AC) is protective to Liver tissue and aids in breaking down excessive mucus.

Green Tea and White Tea may be consumed as tea or in extract form daily.

Vitamin C may be consumed to bowel tolerance. This is anywhere from 1 to 6 grams daily. (Bowel tolerance means up to the amount that causes gastrointestinal upset.)

Selenium, Vitamin E and Zinc can be included in a good daily multivitamin for their antioxidant properties.

Healthy Gastrointestinal Tract

The gastrointestinal tract is responsible for absorption of water, nutrients, vitamins and minerals and even produces some nutrients with the aid of friendly bacteria. Gas, bloating, indigestion, changes in bowel habits, nausea and vomiting are all symptoms of imbalance and can be used to guide treatment.

Fiber aids in regulating lipid levels, removes toxins and provides bulk for healthy bowel habits. Soluble and insoluble fiber sources such as oat bran, apple pectin, flax and whole grains should be included. Bloating after taking a fiber supplement can sometimes indicate a sensitivity to that source. This occasionally occurs with psyllium, in which case changing to a different form may be indicated. It is essential to include adequate water intake when taking fiber supplements.

Fish Oil and Essential Fatty Acids provide the necessary building blocks for cell membranes. They also have anti-inflammatory properties and aid in regulating lipid levels. These oils are more sensitive to going rancid and should be refrigerated. 1 to 2 tablespoons may be included daily.

Ginger is helpful in tea or herb form for controlling nausea and vomiting.

Glutamine is an amino acid that aids in maintaining

a healthy gastrointestinal lining and helps to repair gastrointestinal damage. It can also be helpful in managing diarrhea. 1 to 2 grams of powdered glutamine may be mixed in smoothies or water.

Milk Thistle is restorative to the liver, and aids in liver cell regeneration. Milk thistle can be consumed in capsule form or purchased as seeds and ground in a coffee grinder. When used this way, 2-3 tablespoons daily can be sprinkled on salads, in soups and in smoothies.

Probiotics (Acidophilus, Bifidus, lactobacillus spirogenes) help to maintain balance of good and dangerous bacteria and compete for the food the dangerous bacteria need to grow and cause us problems. Lactobacillus acidophilus and bifidus may be found in yogurt with active culture or in supplements and can be consumed freely without known side effects. It should be refrigerated to maximize shelf life. Patients on antibiotic therapy, diagnosed with thrush, diarrhea or constipation should consider taking probiotics 2 capsules 3 times daily with meals. For thrush a capsule can also be opened in some water and used daily as a mouth rinse.

As with any treatment protocol, check with a licensed specialist prior to beginning a supplement regimen. Hopefully you have found this information a useful starting point in finding a protocol that is best for you at this time in your life. Each person is individual and therefore, what works for one person may not always be indicated for someone else. Lastly, be patient with this process – lifestyle changes take time and discipline to become permanent fixtures in our day-to-day routine.

JoAnn Yanez, N.D. is a Doctor of Naturopathic Medicine, Arizona Licensed Physician and graduate of the Southwest College of Naturopathic Medicine. She maintains a consulting practice in New York, working with HIV and chronic disease. Dr. Yanez can be seen lecturing on these topics across the country and may be reached at www.DrYanez.com for further information and consultations.

To place an ad or announcement: Submissions should not exceed 75 words; we will cut to fit or return them if they do. We reserve the right to edit content and to reject anything considered unfit for publication. Mail copy to the address below. If you wish your ad or announcement to run more than once, multiply the cost by the number of months you wish it to run. Be sure to include your company or personal name, telephone number, and/or address in the ad. Ads and announcements appear in both our print and Internet editions. Please note that Body Positive does not run personal ads.

Deadline: Ads and announcements must be received at least one month prior to issue date. For example, January 1 is the deadline for the February issue.

Cost/Address: Ads and announcements cost \$35 per ad per issue, payable to Body Positive, Inc. Send ads to:

Ads and Announcements
c/o Body Positive
19 Fulton Street, Suite 308B
New York, NY 10038

HEALTHY LIFE CHOICES PROJECT

HIV-positive individuals experiencing chronic diarrhea (soft or loose stools three times per day for three weeks or more) are invited to participate in the Healthy Life Choices Project, a controlled clinical trial to determine whether strategies related to diet and behavior can help reduce the frequency of diarrhea in people with HIV. The study, which is noninvasive, investigates a combined dietary and behavioral intervention using normal foods to improve the symptom of diarrhea. No medication is given as part of the study, and participants may remain on their current medications, including antidiarrheal medications. For further information, call Ann Chung at the Columbia University School of Nursing Center for AIDS Research, 212-305-0216.

PROJECT 50+-: HIV+ PEOPLE OVER 50

When you are HIV-positive and fifty years of age or older it is often difficult to cope. Coming to terms with HIV creates difficult challenges. Coming to terms with your own aging is often another personal challenge. We offer you the opportunity to discuss these issues in a safe environment, join our Project 50+. Complete a confidential

questionnaire, participate in individual or group sessions and earn up to \$240 for the entire study. For more information or to register call: Arlene Kochman LCSW, Yale University School of Medicine, Dept of Epidemiology and Public Health, @ Callen-Lorde Community Health Center 212-271-7203.

MACROBIOTICS

Achieve an invincible immune system and optimize vitality through macrobiotics. "A return to a more balanced way of life, including a diet centered around whole grains and vegetables, will help prevent, stabilize, and in some cases relieve AIDS." (Michio Kushi and lex Jack, *The Macrobiotic Path to Total Health*, 2003) Enter the promotional code BP0905 o receive a free macrotreat at www.gomacro.com

ATTENTION: HIV+ PRISONERS

HIV+ Hope Behind Bars (H+HBB) is a bi-monthly treatment info newsletter by and for HIV+ prisoners which is sent out free to HIV+prisoners and others. To be placed on our mailing list, send your name, inmate number, and institutional mailing address to: H+HBB, 962 Mimosa St. South, Salem OR 97302.

PSYCHOTHERAPY

Now available for private practice: Psychotherapist Linda Saisselin, LCSW, ACSW. Over 25 years serving the LGBTQ community. Specializing in issues surrounding individuals and couples infected/affected by HIV/AIDS. Medicare, some managed care insurance, and affordable sliding scale. Convenient W. Village location. Free initial consultation: (917)821-1685.

TA CLEARINGHOUSE

The TA Clearinghouse (www.taclearinghouse.org) is a Web site for NYC and Tri-County (Westchester, Rockland and Putnam) AIDS organizations & PLWHAs. Our mission is to help CBOs and PWAs learn more about available resources including publications, trainings, jobs, and funding. Additionally, the TAC links to HIV-related information and technical assistance tools to support agency infrastructure and community advisory boards. Funding is provided by Title I of the Ryan White CARE Act and administered by MHR/HIV Care Services

PROJECT LIFT

When you are HIV+ and have suffered from early, unwanted sexual experiences,

it is often difficult to cope. If you are dealing with this and are a woman or gay man, we offer an interview, assessment and group therapy. Up to \$375 for your project time. Complete confidentiality assured. Call Arlene at 212/271-7203. Sponsored by Yale Univ./Callen-Lorde Health Center.

STUDY FOR HIV-NEG. GAY/BI MEN

Previous research tells us that people who are depressed have a hard time making the changes they want to make in their lives. It also suggests that there is probably a connection between depression and risky sex in gay and bisexual men. Project CHANGE wants to know if treating depressed HIV-negative gay and bisexual men with an anti-depressant – one that doesn't have sexual side effects – can help them stay safer. If you think– or know– that you're depressed but are not currently in therapy or taking medications to treat it, you might be eligible. Participants in CHANGE are compensated for completing surveys and receive one-on-one safer sex counseling. Call 212-263-0362 to find out more and see if you are eligible.

NEW RESEARCH STUDY FOR FATIGUE

HIV-positive men and women with severe and persistent fatigue may be eligible for a new research study of Provigil (Modafinil). Provigil is an approved and marketed medication to improve wakefulness in patients with excessive daytime sleepiness associated with narcolepsy. It is now being studied for fatigue. The study is intended to determine if Provigil can effectively treat fatigue that is persistent and severe enough to interfere with the person's daily activities and does not have an untreated underlying cause. Individuals considered for the study will be on antiretroviral medications. During the 4-week study, all participants meet with the study psychiatrist weekly or biweekly (during the day) at New York State Psychiatric Institute/Columbia University Medical Center. All patients will get Provigil, but for some there may be a 4r week delay. Responders may continue to receive Provigil for another two months; non-responders are offered other medical options. Compensation is given for clinical assessments (questionnaires) and tests of concentration, alertness and memory. For information, call: Dr. Judith Rabkin at 212-543-5762.



Please tell us your opinions about Body Positive Magazine. You can return this survey anonymously but if you include your name at the bottom, it will be separated from your responses and will make you eligible for a lottery to win a free one-year subscription to Body Positive Magazine.

How often have you read Body Positive Magazine before this issue?

Never Once or Twice Three to Six Times More than Six Times

Where did you get this copy of Body Positive Magazine?

In the Mail At a Clinic or Doctor's At a Community Center Other: _____

What kind of articles do you find the most useful?

Please rate each type of article on a scale from 1-5, with 1 as "least useful" and 5 as "most useful."

| | | | | | |
|--|---|---|---|---|---|
| Psychological and mental health issues | 1 | 2 | 3 | 4 | 5 |
| Financial concerns and benefits | 1 | 2 | 3 | 4 | 5 |
| Articles about HIV treatments | 1 | 2 | 3 | 4 | 5 |
| First-person and opinion articles | 1 | 2 | 3 | 4 | 5 |
| Fitness and nutrition articles | 1 | 2 | 3 | 4 | 5 |
| Updates on public policy | 1 | 2 | 3 | 4 | 5 |
| Info about HIV programs and services in New York | 1 | 2 | 3 | 4 | 5 |
| Info on natural, holistic, and alternative therapies | 1 | 2 | 3 | 4 | 5 |

Are there any topics that you would like to see covered in Body Positive Magazine?

(Add another page if needed)

Optional: Please include your name and mailing address to be included in a drawing for a free one-year subscription to Body Positive Magazine.

**PLEASE FAX TO 212-566-4539 or
MAIL TO BP SURVEY, 19 FULTON ST., SUITE 308B, NY, NY 10038**