

# AIDGwinnett

Gwinnett • Rockdale • Newton  
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## *the 411*

a booklet of important information  
for clients of AIDGwinnett

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## Know your rights and responsibilities

AIDGwinnett maintains a “Patient’s Bill of Rights and Responsibilities” which includes the following.

*You have the right:*

- To be treated with dignity and respect.
- To know the names and professional status of people serving you.
- To privacy.
- To confidentiality.
- To receive accurate information about your health related concerns.
- To know the effectiveness, possible side effects, and complexities of forms of treatment.
- To participate in choosing a form of treatment.
- To receive education and counseling.
- To consent to or refuse care and/or treatment.
- To review your medical records with a clinician.
- To file complaints and grievances when dissatisfied with the treatment you have received.
- To information about services and related costs.
- To be informed about how your health record information may be used and disclosed according to legal guidelines.
- To request or refuse release of your medical records in accordance with legal guidelines.
- To expect your cultural characteristics and experiences to be respected.

*You have the responsibility:*

- To treat clinic personnel and other patients with dignity and respect.
- To seek medical attention promptly.
- To be honest about your medical history.
- To ask about anything you do not understand.
- To follow health advice and medical instruction.
- To report any significant changes in symptoms or failure to improve.
- To respect clinic policies.
- To keep appointments or cancel 24 hours in advance.
- To actively participate in maintaining eligibility for various benefits.
- To seek non-emergency care during regular hours.
- To provide useful feedback about services and policies.
- To make arrangements to pay any fees charged to you.
- To inform staff of changes in your personal information (address, phone number, name change, income status, insurance, etc.) as soon as changes occur.
- To strive to maintain a healthy lifestyle.

## Importance of staying in touch

It is your responsibility to maintain communication with AIDGwinnett and to inform your case manager of changes in your contact information including address, phone and alternate contacts. We may need to call you with an urgent request - but if your contact information is outdated we probably *will not* be able to assist you! Your 411 booklet includes a list of important contact numbers printed on the inside front cover. Keep your list handy or save the numbers in your cell phone, if you have one.

You should also stay updated on our current events and important announcements. Whenever you visit us you should check our bulletin board for new policies, important announcements, news and other useful information. If you have internet access, you should also check the “Information for Clients” section of our web site at least monthly.

[www.aidgwinnett.org](http://www.aidgwinnett.org)

## Case manager appointments

The number of people we serve continues to grow. In order to serve you better, please note that appointments are *required* for consultation with your case manager. Call your case manager in advance to schedule a time to meet. “Same day” appointments are not available and if you arrive without an appointment, you will be required to schedule an appointment for a future date. These rules do not apply during “walk-in times” which are available without a prior appointment Monday afternoons from 2:00 to 4:00 p.m. and Friday mornings from 9:00 to 11:00 a.m.

## Accessing support services

Thanks to the generosity of our local community, residents in the Gwinnett-Rockdale-Newton area enjoy a strong network of programs and services covering a wide range of needs. Many options are available if you need clothing, food, transportation, legal assistance, career development, educational training or other services. See your case manager. Also ask for a free copy of the *Key Contacts* book. It’s an incredible directory of programs and services for people living with HIV! You can also call one of the local helplines directly if you so prefer.

United Way of Metropolitan Atlanta 211 Helpline  
(just dial 211)

Gwinnett Helpline (770-995-3339)

## Clinical care, medications and supportive services are available

AIDGwinnett offers a broad range of medical services at the Ric Crawford Clinic. Primary medical care and antiretroviral drug therapy are available. Specialty care referrals may be available depending on eligibility and availability of funding. Our staff can help you obtain medication through prescription drug assistance programs and the Georgia AIDS Drug Assistance Program (ADAP). Nutritional guidance and counseling are also available. Clinical services are made possible by funding from community support and Ryan White CARE Act Titles I, II and III and provided through a contractual agreement with Gwinnett Infectious Diseases, PC.

## Your Medical Care Team

In order to provide complete healthcare for clients, AIDGwinnett contracts with a team of medical care providers employed by Gwinnett Infectious Diseases. This team includes a registered nurse, three doctors and a nurse practitioner. All share extensive experience in the field of infectious diseases. A family nurse practitioner is a registered nurse with advanced education and clinical training in a health care specialty area. Nurse practitioners work with people of all ages to provide care and information to improve personal health. They serve as the regular healthcare provider for children and adults during health and illness. Depending on the situation, from time to time you will probably see either a physician or a nurse practitioner (or both) when you come to the clinic for an appointment.

## Become a “Star Patient”

*From Poz magazine, Fall 2004*

Medical treatment for HIV requires a partnership between you and your medical care provider. You can make a significant difference in your overall health and wellbeing by taking responsibility and becoming an actively participating patient. According to Poz magazine, a “Star Patient” is one who:

- 1 HAS PATIENCE.** Treatment strategies take time to pan out.
- 2 ASKS QUESTIONS.** If you have concerns about side effects or your prescribed medicines (or anything) just speak up!
- 3 SHARES INFORMATION.** There may be things in your life that affect your ability to take medicine properly or cause medical interactions (such as party-drug use, for example). The more your provider knows about your habits, the better he or she can help match you with the right treatment.

**4 TAKES RESPONSIBILITY.** Many providers prefer patients who know their HIV “ABCs” (or want to learn). But if that’s not you, let your provider know. Either way, you are taking charge.

**5 STAYS THE COURSE.** You may not be organized enough to track symptoms and changes. You may even miss doses and appointments. But take your next scheduled dose as prescribed, and get regular checkups.

In addition, the following tips are drawn from the book *Men Like Us* by Daniel Wolfe under the heading “Making the Most of Your Visits.”

**1 ARRIVE PREPARED.** If it’s a first visit, have medical records sent from your previous provider or bring a copy. Bring a list of all medications you’re taking (including dosages) with you. Take a few minutes beforehand to refresh your memory of your medical history – significant illnesses, injuries or operations you’ve had, medications you’ve taken or are taking, allergies and anything else that may be pertinent – and your familiarity with your family’s health history.

**2 BRING A LIST.** Even for experienced people in a friendly provider’s office, it’s common to feel confused or to forget to ask something important. Start with the most important things first, and outline things in as organized a way as you can. If you’re sick, think about how you can describe the symptoms precisely. Is the pain in your back concentrated in a single spot or generalized through a large area?

**3 IF YOU’VE SEEN OTHER MEDICAL CARE PROVIDERS** for the condition, don’t hide that fact. Briefly tell your new provider what the previous doctor did and when. If you’re still seeing someone else, ask your new doctor to give the other doctor a call. If you’ve had tests, bring in the results.

**4 BRING A PEN** or, if you’re sick, a friend with a pen. Going in with someone else can help keep you calm, and – if your friend is willing to take some basic notes – can leave you free to focus on understanding what the provider says. Even if you’re alone, write down information, since it’s hard to remember everything. Always ask for more information if you don’t understand something and remember that follow-up questions can help remind the provider, and you, to explore the options. Dr. Howard Grossman of New York suggests these follow-up questions.

- What’s the name and cause of the illness?
- What happens if I don’t do the treatment?
- Is there anything else I could do to feel better?
- What kind of side effects are there from the medication, and what should I do about them if they happen?
- How long should I expect this condition to last?
- What changes or symptoms should I report to you?
- When’s the best time to call with questions?
- What should I do in an emergency?

**5 GET TO KNOW THE STAFF.** Whether it's the nurse or the receptionist, a provider's staff is his or her support. Ask for help – and be nice!

**6 DO WHAT YOU AGREE TO DO,** or let the provider know when you can't. Providers assume you're taking your medication and, often, that the medication they have prescribed is working. If one or both of these are not true, let them know and explore other options. Don't be intimidated! There's often more than one way to treat something and it's important for both of you to work together.

## You are required to stay in care

Due to regulations of the Ryan White CARE Act, and in the interest of promoting your health and wellbeing, we require that you must be seen by a health care provider at least once every 3 to 4 months so he or she can monitor your health and modify your treatment plan as necessary. Our goal is to maximize your health in partnership with you. Even if you are feeling strong and healthy, you are still required to see a medical care provider on a regular basis because although you may be feeling wonderful, your CD4 cell count and viral load may be at critical levels and this could be dangerous to your health. Only a laboratory analysis can accurately reveal your CD4 count and viral load.

## Please arrive on time

We strongly recommend that you mark all of your appointments on your calendar. Please make any necessary plans for transportation early in advance. If you are working, your employer may require a request for time off several days in advance. Be sure to allow enough time in your schedule for travel and plan to arrive at least 10 minutes early for paperwork.

*"In the past, I missed many of my appointments and this was a major problem. I was unable to get services that I needed. I also got very sick one year because I missed 3 clinic visits, and I was unaware that my CD4 count had dropped to a very dangerous level. I almost gave up. The experience was so frustrating. But now I almost never miss my appointments (or if I can't come I always reschedule in advance) and so now my health is getting much better."*

-John Doe, patient

## Get your labs on time

Whenever you receive an appointment to see the medical care provider, you will also receive an assigned date when you must go to LabCorp for blood analysis. Your assigned date may be as early as 6 weeks before your medical care appointment. The analysis usually includes a check of your CD4 cell count (which is an important part of your body's immune system) and the level of viral load in your blood. Lab results are important because your medical care provider needs this information to help monitor the status and progression of HIV in your body, to guide recommendations for therapy and to predict the future course of HIV.

If you cannot obtain blood analysis at LabCorp during the specific week assigned to you, please let us know immediately. We will probably need to postpone your clinic appointment if your blood analysis is not performed at the right time.

LabCorp is located at 575 Professional Drive (2nd floor, suite 285) in Lawrenceville, in a large blue glass building near Gwinnett Medical Center. Be sure to bring two lab slips with you! In addition, residents of Newton and Rockdale counties may go to LabCorp in Conyers at 1288 C Wellbrook Cir.

## What is my CD4 count and why is it important?

*Information adapted from [www.thebody.com](http://www.thebody.com)*

CD4 cells help to organize your body's defenses against disease. Providers can take a sample of your blood and count the number of CD4 cells. Healthy adults and teenagers usually have a CD4 count of at least 800 cells per cubic millimeter of blood (a cubic millimeter is a very small amount like one small drop). HIV attacks CD4 cells, and as time goes by people with HIV often see their CD4 counts drop. The lower your CD4 count, the greater your chances of getting a number of very serious diseases. When your CD4 count is below 200, the risk of illness becomes severe. Research shows that people with low CD4 counts are much more likely to get sick than people who have a normal amount of CD4 cells. The deadly pneumonia called PCP occurs much more often in people with very low CD4 counts. In one study with over 1,000 patients, almost everyone who got PCP had a CD4 count below 200. Other studies have also shown the same thing: The lower your CD4 count, the greater your chance of getting PCP or other serious opportunistic infections.

## What is my viral load and why is it important?

Information adapted from [www.thebody.com](http://www.thebody.com)  
CD4 counts give you and your provider a good idea of how much damage HIV has done to your immune system – but you also need to know how fast that damage is happening. Viral load tests are a very important clue to how quickly HIV is doing harm. Viral load is a measure of the amount of HIV in your blood. The amount can range from greater than 750,000 copies to less than 50 copies per milliliter. Unfortunately, current drug therapies can not remove HIV completely from the body; but therapy can sometimes help to decrease HIV numbers to less than 50 copies per milliliter which is very good. A viral load less than 50 is often called an “undetectable viral load,” but this is misleading because HIV is still present in the body and can still replicate itself.

Your provider will use your viral load levels to help decide when therapy should be started and what types of medications are best for you.

People with a high viral load are much more likely to get sick or die of AIDS than people with a low viral load. For example, one very important study has followed thousands of gay men since 1984. A few years ago researchers did viral load tests on the very earliest blood samples from that study and then looked at how many of those patients were still alive. The men with the highest viral loads were 77 times more likely to have died of AIDS than those with the lowest viral loads. Other studies in the U.S. and Europe have shown the same thing: A higher viral load almost always means a higher risk of sickness and death.

Studies have shown that when treatment reduces your viral load, it also reduces your chance of getting an AIDS-related infection or dying. Recently, a group of expert

scientists reviewed 18 studies of anti-HIV drugs, which involved over 5,000 patients. Over and over again they found the same thing: The more viral load was reduced, the healthier the patients stayed.

*“ My viral load level was under 50 (undetectable, as they call it) so I thought this meant I could have sex without condoms and my partner would never get HIV. But then my doctor said the viral load test is only for my blood. He said the level of virus in my semen could possibly be much higher than the level for my blood. And the level in my blood could increase again over time. All this made me think twice about having unprotected sex. ”*

John Doe, patient

## Symptoms you shouldn't ignore

Ignoring symptoms can come with very serious consequences! In the spirit of good communication, never hesitate to share your symptoms with your medical care provider, even if you think the symptom is probably “not a big deal.” You should never feel embarrassed about reporting any symptoms – including symptoms in the genital area – as they may indicate a very serious medical problem. Please visit your medical care provider or call us on the phone. Your medical care provider will evaluate symptoms and treat the problem accordingly. The following symptoms are drawn from the book *Men Like Us*, by Daniel Wolfe.

### Symptoms that should send you for EMERGENCY MEDICAL CARE:

- Chest pain, particularly if it radiates down your left arm
- Sudden disturbance in vision, such as seeing sparks or large black spots, or developing partial blindness or loss of peripheral vision
- Sudden disturbance in speech
- Persistent numbness in any part of the body, especially concentrated on one side
- Vomiting blood
- Difficulty breathing, especially with activity
- Any intense, unremitting pain that makes activity impossible
- Unable to keep *any fluids* down
- Fever combined with rash, lethargy (extensive tiredness) and peeling skin

### Symptoms that require a clinic appointment as soon as possible\*

- Unexplained weight loss of more than 10 percent of your weight
- Diarrhea (three or more bowel movements a day) that lasts for more than two days
- Unexplained lump/growth on any part of the body
- Difficulty swallowing
- Skin rashes that last for more than a few days, a change in a mole, or unusual-looking new moles or skin growths
- Constant thirst
- Frequent urination
- Visible blood in your bowel movement or urine
- Fever over 100 degrees

\*Call the clinic to request an appointment. If you call when the clinic is closed and you have an illness or medical situation that is not an emergency but can not wait until the next business day, you may call the physician on call at 770-995-0466. In case of a medical emergency call 911 or go to the nearest emergency room.

## **Counseling services are available**

You can request an appointment to speak with a trained counselor for guidance and support on a broad range of topics. Requesting a counseling appointment is nothing to be embarrassed about and we encourage everyone to try counseling at least one time. Ask your case manager for a referral.

## **Medication adherence is vitally important – especially with HIV**

Your medical care provider may prescribe medication to combat HIV in your body. As the medication works to stop the virus from making more copies of itself, the amount of HIV in the blood (also called viral load) will drop significantly. If you miss a dose of your medicine, however, HIV will be able to reproduce itself in greater numbers. HIV may also develop a resistance to that particular medicine and this could make that drug ineffective. By taking your medication as directed, you help to ensure that viral load reduces over time. A lower viral load makes it easier for your body to strengthen its immune system.

If you ever have difficulty taking your medicines, please call the clinic right away to discuss options with your medical care provider.

## **Questions about your medicine?**

Call the Ric Crawford Clinic at AIDGwinnett with questions about medicines you are taking, side effects, dosages, combinations and other questions. You may also call the Georgia ADAP Pharmacy (1-888-317-8003) to speak with a pharmacist or an associate specializing in HIV medicine Monday through Friday from 8:30 am to 5:00 pm. For questions about ordering medicine contact the AIDGwinnett ADAP/ Medication Manager (678-990-6424).

## **Copays are sometimes required**

The Ryan White CARE Act allows HIV/AIDS service organizations to bill patients a small fee for a portion of medical expenses incurred during clinic visits depending on the type of service provided and the income level of the patient. You may be billed a small “copay” during your clinic visits. The amount is based on your annual income and has an annual maximum cap. Payment is expected at the time of

service, but no one will be denied service due to inability to pay. Because the amount of available funding is limited, we appreciate the payments you make since they allow us to serve more people with top-quality programs and services.

## **Appointments are required for medication pickup**

If medication is ordered for you, your medicine will most likely be shipped to AIDGwinnett as a 30 day supply of pills. If you pickup medicine today, you will probably run-out of medicine in about 30 days (unless you have spare bottles). You must pickup your next bottles *before you run-out* or you will have a serious problem: *no pills to take!*

You are required to make an appointment to pickup medicine. Your appointment should be at least 5 days before your medicine bottles finish in order to avoid missing doses. We recommend that you call at least 5 to 8 days beforehand to request an appointment. Never make the mistake of waiting until the day before you run out of medicine, because “same day appointments” and “next day appointments” are often *unavailable* for medicine pickup as our clinic calendar is often filled. Please call the clinic at 678-990-6420 for assistance in requesting an appointment for medicine pickup.

It is your responsibility to schedule your appointment early enough in the month so that you will not miss medicine.

## **Procedures for specialist referrals**

Depending on your need, you may be given a referral for examination/treatment by an outside medical specialist. This may include a referral to a dentist, for example. If you receive a referral, it is your responsibility to contact the assigned specialist to request an appointment and be sure to take your referral copy with you to your appointment. Please *do not lose* your referral paperwork. Also, don't delay making your appointment. The referral will be invalid after a period of time.

## **Clinic after-hours (after 5pm or holidays)**

If you cannot come to the clinic during regular office hours (because of reasons such as employment or other reasons) you may request an appointment at 5PM or later depending on availability.

Also, if you have a medical emergency, dial 911 or go to the nearest emergency room. If you have an illness or medical situation that is not an emergency but can not wait until the next business day, you may call the physician on call at 770-995-0466.

## **HIV testing and HIV/AIDS support services outside our service area**

Two telephone hotline services are available which can answer questions about HIV/AIDS and other sexually transmitted diseases. They also maintain a database of agencies offering HIV testing. These hotlines can refer you to HIV/AIDS services throughout the United States.

For information specific to Georgia, call the state HIV/AIDS Information Line at 404-870-7775 or 1-800-551-2728.

For national information and resources, call the CDC National AIDS Hotline: 1-800-342-2437 (English), 1-800-344-7432 (Spanish), or 1-800-243-7889 (TTY).

## **Confidential services for notification of past partners**

Most cases of HIV transmission can be attributed to two means of exposure: either unprotected sex with an HIV-positive partner or needle sharing with an HIV-positive partner. If you are living with HIV and you have engaged in any of these activities with someone who was not HIV positive at the time, then he or she may now be HIV positive as a result of that experience. Past partners should be encouraged to get tested for HIV.

Anonymous and confidential services are available to give you the option of notifying your past partners (either directly or indirectly) about the need to get tested for HIV. If they test positive for HIV, they can be linked to receive clinical care, treatment and education.

With some of these notification services, your name is not shared (anonymous notification). You may wish to send a message to a past sex partner to advise them of the need to get tested. Your name is not be revealed unless you specifically authorize it.

- AIDGwinnett Outreach Manager  
678-990-6421
- www.INSpot.Org web site  
*a service of San Francisco Department of Public Health*
- East Metro Health District  
770-339-4260 extension 340

## **Moving? Plan ahead!**

If you are moving, you will need to take certain steps in advance in order to ensure a smooth transition. You should do the following:

- 1** Call the CDC National AIDS Hotline (see page 12) to locate an HIV/AIDS service organization in your new city. You should call the HIV/AIDS service organization as soon as possible to begin the registration process with your new agency. Start the transition process early to avoid problems.
- 2** Prepare in advance for all the medication you will need. Do not runout! In certain situations we may be able to release your medication to a person you trust if you sign a release form in advance. Your friend can then bring your medication to you.
- 3** Request a complete copy of all your current medical records or ask your doctor's office to have them faxed to a medical care provider or someone you trust in the new city where you will be living.

## **Documentation of your income and residence**

All clients must provide proof of income and residence twice each year (February and August). If you do not comply with this requirement your status will be converted to "inactive" and you will not receive any services until you comply. See your case manager.

## **Orientation workshop**

AIDGwinnett conducts an orientation workshop which covers agency rules and procedures; client responsibilities; services available for you; important HIV facts; important contacts and resources; helpful suggestions; how to advocate for yourself; and much more. Call 770-962-8396 for the time and date.

This workshop is mandatory for all new clients and also for all past clients who are now reactivating after being inactive for a period of time. In addition, the orientation workshop is optional for current clients (already-existing and currently active) *but strongly recommended* because the workshop covers such useful, important topics. No reservation is required. This workshop is not offered during holidays.

## **Do I need to practice safer sex even though I am HIV positive?**

HIV positive persons should practice safer sex techniques (such as using a condom) during sex in order to prevent the transmission of other sexually transmitted diseases, some of which can result in

death when combined with HIV. In addition, safer sex techniques<sup>†</sup> can help reduce the risk of passing-along HIV to other people. But even if an HIV positive person has sex with a partner *who is already* HIV positive, practicing risk reduction and safer sex techniques is still a good idea because these can help reduce the risk of possible re-infection with HIV (also known as “superinfection”). Re-infection may help HIV become resistant<sup>††</sup> against certain types of drug treatments, possibly leading to a boost in viral load (viral escape) and limiting the list of available options for antiretroviral drug therapy. The following paragraph is quoted from Joel N. Blankson, MD, PhD, an expert in the field of HIV/AIDS research. Dr. Blankson is a professor in the division of infectious diseases at Johns Hopkins University School of Medicine in Baltimore. Please feel free to contact your health care provider if you have specific questions or concerns or desire further clarification.

“ There are now sufficient data suggesting that superinfection can occur. Significant drops in CD4 counts and transient increases in viral loads often accompany super-infection.

Furthermore, a recent retrospective analysis showed a very rapid progression from sero-conversion to clinical AIDS in five untreated patients with dual HIV infection (range of 1.0 to 3.4 years). It should also be noted that patients on HAART with undetectable viral loads may be at increased risk of superinfection, as the levels of HIV-specific neutralizing antibody and effector CD8 T-cells have been shown to decline over time when viral replication is suppressed.

There is also the danger of infection with drug-resistant viruses, which would have a selective advantage over wild type virus in patients on effective antiretroviral therapy. Based on these findings, HIV-infected people should be advised to practice safe sex with other HIV-infected partners in order to prevent HIV superinfection and all of its associated consequences. In addition, safe sex practices are indicated to prevent transmission of other sexually transmitted infections. ”

*From Blankson, J. HIV Superinfection: Can Patients Be Infected Twice? The Hopkins HIV Report, May 2004.*

<sup>†</sup>In addition to using condoms, other risk reduction techniques also exist. Ask your medical care provider for guidance. You can also participate in the AIDGwinnett “Positive Skills for Thriving” program to learn more about topics such as risk reduction, safer sex, condoms, HIV testing and partner communication.

<sup>††</sup>Scientists have documented the phenomenon of drug resistance acquired through superinfection (also referred to as “DRATS”) in clinical studies with humans as well as lab animals.

# AIDGwinnett

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AIDGwinnett is a non-profit charitable organization founded in 1991. AIDGwinnett is *not* a government agency. The programs and services of AIDGwinnett are made possible through the generosity of caring individuals like yourself, volunteers and strong community support.

Donations to AIDGwinnett are tax deductible to the full extent allowed by law.

Clinical services at the AIDGwinnett Ric Crawford Clinic are funded in part through Titles I, II and III of the Ryan White CARE Act. Clinical services are provided through a contractual agreement with Gwinnett Infectious Diseases, PC.

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generous donors and supporters,  
including but not limited to:*

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with AIDS (HOPWA) Program  
AIDSWalk Atlanta  
The Atlanta AIDS Partnership Fund  
East Metro Health District  
Georgia Department of Human Resources,  
Division of HIV Prevention Services  
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