



# ANNUAL REPORT

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## THANK YOU FOR YOUR CONTINUED SUPPORT

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### *A message from Jay Rudman, President and CEO*

**I**t's a news headline seen time and again in recent years: Severe economic recession puts strain on local not for profits. AIDS Care has felt this strain. The general economic decline and the associated government fiscal crisis have meant budget cuts, delays in grant payments and changes in outpatient reimbursement. There are even more changes and challenges to funding on the horizon.

Yet, we are buoyed by the continued generosity and loyalty of donors like you who make the work of AIDS Care possible through your never-ending support. With your help, AIDS Care has experienced many successes in the past year – even as a newly formed organization born during a period of severe recession and exploding government debt.



Some of these successes are outlined in the following pages: the opening of AIDS Care's new Day Health program – the only such program in the state outside of New York City; the expansion of clinical trials; growth and development of HIV/AIDS prevention programs; creation of a new planned giving society and an evolving strategy of 'treatment as prevention.'

While noting these successes, we have kept an eye on the future and the challenges that lie ahead. Everyone at AIDS Care is now engaged in a strategic planning process to define and shape the agency's vision for the future to ensure its long-term vitality and viability.

The good news is that the strategic planning process has confirmed that AIDS Care's comprehensive, one-stop shop model of care is on target. AIDS Care's model of a coordinated, patient-centered approach is now considered the future foundation for health care delivery in the nation. For years, AIDS Care and its legacy organizations have provided care for consumers with complex medical and psychosocial needs. The merger has allowed us to enhance and integrate our wide array of medical, social and prevention services including: outpatient care, case management, testing, housing, transportation, nutrition, treatment adherence, day health and behavioral health. As we move to the future, the goal is to maintain and improve the one-stop shop model, to continue to be patient focused and ultimately, to become more inclusive of the populations served. Research of community needs as well as AIDS Care's capacity and resources will be essential in determining how we can fill gaps in care delivery without duplicating efforts that already exist.

It is a challenging time, but an exciting one as well as we strive to become a clinical center of excellence for populations new to us while maintaining comprehensive care for people living with HIV. We hope that you will join us and continue to show your support of AIDS Care as we move forward into the future.

*Jay Rudman*

*Thank you!*

# HIV TREATMENT AS A PREVENTION TOOL: FAQ

## DR. BILL VALENTI, CO-FOUNDER AND PHYSICIAN AT LARGE

*Dr. Valenti has written about this topic on his blog, <http://aidsevidence.blogspot.com>, and recently spent two weeks in Rome at the International AIDS Society Conference where Treatment for Prevention was a hot topic.*

### WHAT IS MEANT BY HIV TREATMENT FOR PREVENTION (T4P)?

Treatment 4 Prevention or “T4P” is a term describing the use of antiretroviral drugs (ARVs) in people with HIV to reduce the risk of passing HIV to others. The rationale is that ARVs reduce the amount of virus in the patient’s blood (measured by viral load testing). Higher viral loads have been linked to increased risk of passing HIV to sexual partners.



### WHERE DOES HIV TESTING FIT IN ALL OF THIS?

T4P is an emerging area that recognizes that voluntary HIV testing and diagnosis is the first step to accessing care.

### SHOULDN'T EVERYONE WITH HIV BE ON ARVS?

We’ve always believed in early treatment at AIDS Care. Now, it’s looking more and more like the answer is yes. ARVs have not usually been used with the goal of reducing the HIV-positive person’s risk of passing the virus to others. The one exception is in the case of pregnant women where ARVs reduce the risk of passing on HIV to the infant during pregnancy or delivery.

### DO WE KNOW WHETHER T4P WORKS OR NOT?

We do now. The results of a multi-national study were reported at the recent International AIDS Conference in Rome, Italy (July 2011). In heterosexual couples (one partner HIV-positive/ one HIV-negative), there was a 96% reduction in HIV transmission when the positive partner was taking ARVs compared with couples in which the positive partner’s ARV treatment was deferred.

### WHERE DOES AIDS CARE FIT IN ALL OF THIS?

The merger of AIDS Rochester (ARI) with AIDS Community Health Center (ACHC) also merged a strong active HIV testing and prevention program (ARI) with an innovative HIV medical program (ACHC).

### WHAT’S THE BOTTOM LINE?

AIDS Care is poised to do T4P and to make a difference. The pieces of the puzzle are in place to make T4P happen. We have prevention activities that include education, HIV testing and outreach and a medical care program that includes an aggressive approach to HIV care.

## THE IMPACT OF EDUCATION AND OUTREACH:

**A**IDS Care targets outreach and education efforts to populations most at risk: women, minorities, intravenous drug users and the Lesbian Gay Bisexual & Transgender (LGBT) communities. Under the direction of Steven Price, the Prevention Services team employs a variety of evidence based approaches to inform and educate both consumers and the general public about the importance of getting tested and reducing the risk of spreading HIV/AIDS and other sexually transmitted diseases. The past several months have provided prevention with opportunities to creatively serve individuals in our community at-risk for HIV.



In May, Lucia Colindrez-Vasquez and the Women’s Prevention team collaborated with Latinas Unidas to host “Para Tu Salud Mujer Latina,” a health event geared specifically toward females of all ages in the Latino/Hispanic community. The event was held in AIDS Care’s new Adult Day Health area at the Monroe Square location and 110 Latinas were in attendance. City of Rochester At-Large Councilmember, Jackie Ortiz, served as mistress of ceremonies, while several physicians, Dr. Amneris Luque, Dr. Gladys Velarde and Dr. Constantino Fernandez, presented on medical information relevant to Latina women: HIV and STDs in Latina women, heart disease prevention and education and the importance of OB/GYN care, respectively.

Workshops throughout the day centered on physical well-being, communication, emotional health and stress reduction. A workshop presented by Annette Ramos entitled, “Mothers & Daughters: A Necessary Conversation” was of particular interest to many due to the recent rise in HIV/AIDS diagnoses in persons under 25 and the concept of education starting at home. Ramos’s workshop featured several strategies designed to engage and empower mothers and daughters to have an open dialog about sex and other difficult topics through use of non-confrontational body language and positive reinforcement. The ladies were also able to enjoy raffle prizes, health-fair tables, breakfast, healthy lunch, and an exciting pre-lunch Zumba workout. AIDS Care provided free HIV and STD testing throughout the day with eighteen women testing.

At the end of June, AIDS Care provided several annual testing events in recognition of National HIV Testing Day and tested 165 people. The first event was held at Monroe Square Park, the second event at AIDS Care’s Syringe Exchange Program on Central Avenue, and the third at J C Boriquen Unisex Salon on North Clinton



## AIDS CARE'S PREVENTION SERVICES TEAM IS MAKING A DIFFERENCE!



Avenue. The third event occurred at a salon that participates in AIDS Care's new Get It Done Initiative. The incentive of a free haircut for those testing brought in 18 Latino men. Twenty five percent of all individuals tested during HIV testing day events were Latino, which was an increase from previous years and further demonstrates the efficacy of AIDS Care's outreach efforts within the Latino community.

On June 30, AIDS Care was cited by the Human Rights Campaign as one of 27 Leaders in LGBT Healthcare Equality according to their annual Healthcare Equality Index. Erik Libey, Associate Director of LGBT and Rural Services at AIDS Care, was quoted in the Human Rights Campaign publication: "The philosophy of inclusion within our organization extends beyond our paper policies and is put into practice daily by our employees. The inevitable outcome has been attracting more LGBT consumers whose involvement in our agency has further built an inclusive culture and has led AIDS Care to becoming a center of excellence in care for LGBT people."

While celebrating this accomplishment and the legalization of gay marriage in New York State, AIDS Care's LGBT program (sometimes referred to by their website name, [www.everybodysgood.com](http://www.everybodysgood.com)) fittingly scored a win at the Rochester Gay Pride Parade for its creativity and ability to capture this year's theme, "It's a Gay World After All!"

## ADULT DAY HEALTH SPOTLIGHT: “I HAVE HIV. IT DOESN’T HAVE ME!”

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**O**n May 23, AIDS Care hosted its Grand Opening and Ribbon Cutting Reception for the new Adult Day Health Program, the first of its kind to be offered outside of New York City. Day Health participants mingled with staff, board members and guests from the community to celebrate the culmination of several years of research and program development. This program intends to improve a participant’s health by providing a positive, community-based experience with a full range of services. As the guests enjoyed the Ribbon Cutting festivities, sincere gratitude was expressed for all who played a role in the program’s implementation. It was apparent that this program was a labor of love and something very unique and special. Several months have passed since the program officially opened its doors at the end of March. In conversations with participants about what Day Health means to them, the responses are overwhelmingly positive. This program is definitely living up to its expectations!

Tony was one of the first participants to sign up with the Adult Day Health Program and is nothing less than pleased. He moved here several years ago from Florida where care was limited and no program like this existed. “Moving here saved my life,” he says. When he first arrived at AIDS Care (which was AIDS Community Health Center at the time) in 2006, his kidneys were failing and the physicians made some adjustments to his medication regimen. He also needed to attend drug rehabilitation. He would come to the pharmacy (Pleasant Street Apothecary) for his medication, “just to get out of the house and see the staff.”

Day Health has given him a sense of relief – he has somewhere to be where he has friends who know what he is going through because they are faced with the same challenges. Tony attends the program daily, and even comes after his dialysis, “We make it fun. Everybody feels like family.” He particularly enjoys the core groups (groups designed to address specific health concerns) and educational programming. “I don’t take it all in at the moment. I take it in afterward...like learning new things that could have helped me win HIV Prevention Bingo!”

“I learn something new every day,” says Regina, another Day Health participant. New topics come up in groups and participants are encouraged to bring ideas for guest presenters to the Day Health staff who work to create a program and groups that are informative, educational, and also fun. For example, another participant was going through some personal issues and a representative from Alternatives for Battered Women was requested to present to the group. Staff state that participants who are willing to share what is uncomfortable or challenges in life help us to plan programs that address pertinent issues such as violence at home and drug use.

“I come on Tuesday for Art Therapy,” says Regina. “I had some issues to work on from childhood and it has been very helpful.” Regina has been extremely influential in encouraging new people to try Day Health and several support groups offered at AIDS Care. Her fiancé attends one of the Men’s Groups. Although he is not HIV positive, he is affected by HIV and the information and support has been beneficial. She also prompted a participant, Miguel, to join Day Health. “I’m so glad I did. Staff are great! We have started a weight loss support group,” he says.

This was not the first mention of the program Registered Dietitian, during the Day Health participant interviews. Participant, Ulises, described her as, “the greatest dietitian on this planet! I have completely different eating habits than I did six months ago and I feel much better!” She provides oversight of the meal program offered daily to participants, as well as the congregate meal that takes place every Wednesday at AIDS Care. “I’ve learned about protein substitutes and vegetables” says Shirley, another participant. Several other participants remarked the nutrition programming has also taught them the importance of drinking water and eating less sugar. The core groups in Day Health will incorporate Nutrition Services to inform participants on making healthier food choices to help support a suppressed immune system, as well as other major health compromising conditions, such as diabetes or Hepatitis-C.

AIDS Care offers a Hepatitis-C program which benefits Day Health participants. This group is a collaboration of several AIDS Care team members from various departments. This “silent disease” presents with very few symptoms, so testing is encouraged, as well as providing education on living with the condition. “They are good people...and offer phenomenal education programs trainings to learn more,” says Shirley, “I want to educate others (participants) because they still have a chance. If I had this program in 1992, I wouldn’t have lost 20 years.” In addition to the Hepatitis-C program, Shirley mentioned other meaningful recreational programs offered in Day Health such as art therapy and gardening.

The resounding message from the participants interviewed was: they now have a place where they have a sense of community, have made friends and have a sense of purpose. Not only did they remark about enjoying the groups and programming, but also expressed gratitude for the concern and care for each individual. Every Day Health participant has a Case Manager. Ulises remarked, “I have a learning disability, and the Day Health Case Managers take me aside and explain things to me. Sometimes it takes a while for things to sink in. I also get help from my peers – my friends notice if I look confused and tell others to be quiet.”

One participant, Carla\*, had wanted to give up before she started coming to AIDS Care. Her mantra, which had been, “I guess I want to live,” has changed to, “I do want to live now.” She not at all motivated home. She came in for an appointment with her provider and saw people in the Day Health area and was prompted to join. She remarked on the cleanliness and brightness of the Day Health area and loves Stretch and Flex (a health exercise program offered twice a week) and many of the educational programs. “They’re here to help me and I’m going to soak it in like a sponge!” She also discussed some of the stigma and negative interpersonal aspects of living with HIV, “Some families shun you when they find out you’re positive.” The program has offered her a second family through friendship with others going through similar circumstances.

AIDS Care’s Adult Day Health program has proved to be a safe environment where participants learn skills to help with the challenges faced. “I have HIV; it doesn’t have me,” says Carla, “It had me then, but it doesn’t have me now.” This Adult Day Health Program and its participants are a constant reminder and just one amazing example of why AIDS Care really is “The Center for Positive Living.”

\*Protecting the privacy of our patients and clients is a top priority at AIDS Care. To protect the privacy of the individual, her name has been changed.



## CLINICAL TRIALS AND PATIENT SATISFACTION:

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**D**r. Roberto Corales serves as Chief Medical Officer at AIDS Care; he is also Principal Investigator of AIDS Care's Pharmaceutical-based Clinical Trials and the Site Leader, Clinical Research Site of the University of Rochester's AIDS Clinical Trials Group (ACTG). When asked about what he'd like to discuss for the 2011 annual report and meeting, he expressed an interest in sharing his thoughts on what it means to be a 'Center of Excellence.' Dr. Corales mentioned many factors that would contribute to clinical excellence in HIV: evidence-based medicine, certification of HIV specialists, participation in national and state organizations (NYS AIDS Institute HIV Quality of Care Advisory Board), professional affiliations, and the presenting and sharing of data on best practices to clinicians at conferences. Two topics were of particular importance: clinical research and patient satisfaction. "Excellence cannot be achieved without clinical research," says Corales, "and AIDS Care aims to be a leader, not a follower, in both research and our delivery of care."



### CLINICAL TRIALS

AIDS Care has approximately 12 different pharmaceutical trials underway at the present time and several types being administered. In early access trials, the United States Food and Drug Administration (FDA) allows promising HIV/AIDS drugs to be used before final approval. AIDS Care has been selected to participate in many Early Access Trials, giving many patients expanded treatment options.

AIDS Care also participates in National Institute of Health (NIH) -Sponsored Clinical Trials as a part of the University of Rochester's Adult AIDS Clinical Trials Group (AACTG). The US AACTG is a program of the NIH and is the largest HIV clinical trials organization in the world. Other types of trials offered at AIDS Care include Pharmaceutical Company Sponsored Trials and Investigator-Initiated trials. The trials offered include those for patients who have been on medications that have failed, never taken drugs before (treatment naïve, comparison trials and observational trials. These trials may collect information on new agents, drug-drug interactions or head-to-head comparison.

One of the many successful trials at AIDS Care came in 2006. A patient was very sick, and had been HIV positive for over 20 years (about as long as the HIV/AIDS epidemic itself). This patient had used almost every option for treatment regimens and was unwell and experiencing severe night sweats. A new drug was available for trial – an integrase inhibitor and a pharmacology 'cocktail' was formed based on the patient's resistance profile. After six months in the study, the patient was clinically improved. The patient started to travel and took a cruise to Ireland, traveled Europe and also Alaska. The patient makes the final decision whether or not to participate in a trial, AIDS Care simply provides the vehicle.

## WHAT DOES IT MEAN TO BE A “CENTER OF EXCELLENCE?”

Clinical Trials division (ACTG, Pharmaceutical-based, and investigator-initiated trials) provides AIDS Care with the opportunity to be involved in cutting edge research and help determine whether a specific trial would be appropriate for AIDS Care and its patients. AIDS Care staff works with the ACTG leadership and pharmaceutical companies (through advisory boards and marketing research) to assess and position AIDS Care as a competitive site. Because of our solid relationships AIDS Care was able to be chosen as a site in highly competitive studies including: “first-in-class” compounds and therapeutic vaccines – all with the goal in changing guidelines. As AIDS Care continues to be chosen as one of a limited sites, it further demonstrates that we are becoming a ‘Center of Excellence’ in research for HIV care not only in the Greater Rochester and Finger Lakes areas, but possibly beyond.

### PATIENT SATISFACTION

The results of AIDS Care’s Patient Satisfaction Survey indicated high ranks (good to excellent) in nine different areas: ease of getting care, wait time, payment, facility, front desk, nurses and medical assistants, providers, other staff and general satisfaction. One respondent stated, “I honestly find all staff and quality of care I receive at AIDS Care to be excellent across the board. I cannot imagine getting a higher level of treatment.” Comments relayed on the survey also indicated statements such as, “I like coming here and it’s a comfortable place” and, “I have always been extremely satisfied! I cannot imagine having to go somewhere else.”

*Some of the highlights:*

- 97.4% of patients report that they would send their friends and relatives to us.
- 98% rate “Provider listens to you” as good to excellent
- 99.3% rate “Provider spends enough time with you” as good to excellent
- 97.4% rate “Provider gives you good advice and treatment” as good or excellent
- 95.5% rate “Front Desk is friendly and helpful to you” as good or excellent
- 99.3% rate “Nurses and Medical Assistants are friendly and helpful to you” as good or excellent

The ability of AIDS Care to provide evidence-based, “cutting edge” medical expertise in a manner that provides and inviting, safe medical home is critical in becoming a ‘Center of Excellence.’ In this evolving world of HIV/AIDS care, it is not only important to deliver comprehensive medical care, one needs to continue in being pioneers by engaging in activities which help change, rather than simply follow, guidelines.

## FINANCIAL SUMMARY

### PROGRAM REVENUE: \$9,740,000

Pharmacy .....	38%
HIV Primary and Specialty Care .....	22%
HIV Case Management, Prevention, Education, and Community Outreach .....	37%
Other .....	3%

### EXPENSES \$8,978,000

Pharmacy .....	12%
HIV Primary and Specialty Care .....	31%
HIV Case Management, Prevention, Education, and Community Outreach .....	48%
Other .....	9%

**Pharmacy:** Pleasant Street Apothecary is a full service, on-site pharmacy that serves AIDS Care patients as well as the general public. The three full-time Pharmacists have over 40 years of combined expertise in managing complex HIV/AIDS medication regimens.

**HIV Primary and Specialty Care:** AIDS Care offers a comprehensive model of care in which patients can receive primary and specialty care in one convenient location. Accomplished medical practitioners provide state-of-the-art HIV specialty care, and the active clinical trials research program offers patient access to promising new treatment therapies. Patients also name access to a multidisciplinary team which includes medical case management, nursing, treatment adherence, nutrition and Adult Day Health.

**HIV Case Management, Prevention, Education, and Community Outreach:** AIDS Care offers a full range of supportive services including Medical and Community Case Management, Behavioral Wellness, Substance Abuse Counseling Services, Support Groups, Housing and Transportation Assistance as well as Prevention, Education and Outreach programs to at-risk individuals.



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