

5 FIVE BOROUGH AIDS MENTAL HEALTH ALLIANCE

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Long-Term Living with HIV – A Life Undiminished *An Interview with John Patrick Dugdale*

Submitted by Tim Hunt, LCSW, CASAC

On the day that I met John Dugdale to conduct this interview, I saw him from a distance in the middle of Hudson Street. Cane in hand, he appeared to have lost his way to the sidewalk and was headed

straight into a bus that had halted to pick up passengers. John is without vision in one eye and has only 5% vision in the other due to HIV related Cytomegalovirus (CMV) and a stroke caused by a rare HIV related blood clot in November of 1993. On the day we met, his seeing-eye dog, Manly, was not with him. A man waiting to board the bus had grabbed his arm and said, "Mister you should get out of the street." He was however, determined to make his way independently by

following the faint white lines of the bike lane. Clearly, John had not planned for two passenger buses to be parked out in the street. As I approached, I heard John say emphatically to the would-be "good neighbor" who was attempting to stop an accident in progress, "...leave me alone! I know what I'm doing!" When I approached and let him know I was

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A Letter from the Editor
Tim Hunt,
LCSW, CASAC

Welcome to the Winter 2004-2005 edition of the Five Borough AIDS Mental Health Alliance (FAMHA) newsletter! In this issue we examine the topic of long term survival of HIV/AIDS. The topics that we tackle here are particularly crucial as the

HIV/AIDS epidemic has moved from a crisis model into a model where daily self-care behaviors can impact a person's disease status. HIV/AIDS is now a disease process that requires coping and adaptation in the face of many stressors over years and perhaps decades. In the Fall 2004 edition of the FAMHA newsletter, we described some of the current theories that account for prevention fatigue and safer sex burnout. In this issue, we focus on the journeys of two long term survivors of HIV/AIDS and specifically on how they are not only surviving, but thriving. Pertinent to this discussion, Solomon, Ironson, Balbin and Fletcher (2002) reported the results of a five

year study examining the psychoimmunology of health and long term survival in persons with

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John Patrick Dugdale *Spectacle, 1999*

5 FIVE BOROUGH AIDS MENTAL HEALTH ALLIANCE

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From the Desk of Lloyd I. Sederer, M.D.,
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the New York City Department of Health and Mental Hygiene,
is a regular contributor to the quarterly FAMHA newsletter.

For the present issue, FAMHA staffers Tim Hunt, LCSW, and Theresa Keane, Ph.D., sat down for a discussion with Dr. Sederer and Andrew Kolodny, M.D., of the Division of Mental Hygiene, Jan Carl Park, MA/MPA, the Deputy Assistant Commissioner for the Department's Bureau of HIV/AIDS Prevention and Control and George DeStefano, the Director of the Bureau's Media & Materials program.. The first part of the discussion was featured in the Fall 2004 FAMHA newsletter. In this issue we present the remainder of the interview, which centered on the need for risk reduction initiatives/ measures to keep in step with the disease of HIV as it changes over time.

Mr. Hunt: Does the risk reduction burnout concept apply to young people if we understand it as a result of years of HIV prevention messages?

Mr. DeStefano: No, I don't think that the burnout concept works for young people. The current thinking reflected in the literature is that the term "complacency" more accurately applies to that particular population. It's important to spell out what may be contributing to young people's sense of complacency because it is a critical variable within the context of the present discussion of why they put themselves at risk for contracting HIV. Some young people think HIV is solely an infection of older people, and there in fact is some truth to that. Statistically, people with HIV/AIDS tend to be clustered in older age groups. Data indicate that at the end of 2002, there were 82,810 people living with HIV/AIDS in

New York City. Eighty-five percent of those persons were between the ages of 30 and 59*. As I previously mentioned one innovative approach to deliver prevention messages to young adults is the DOHMH funded TEACH initiative - Technology Exchange and Capacity Building for Community Health. TEACH, an initiative that targets at-risk young gay men of color, is a collaborative effort of the Columbia School of Public Health, Gay Men's Health Crisis (GMHC) and Medical Health Research Associates (MHRA).

Dr. Keane: Can you share some of the details of the program's model?

Mr. Park: TEACH is an evolutionary way of delivering HIV prevention messages - moving away from the one-size fits all standard of the past to a



Empire Chair in the Gloaming, 1995

comprehensive program of population/culture specific messaging delivered by peers at the local level. The goal of this initiative is to build and sustain the capacity of frontline staff of community based organizations to deliver HIV prevention interventions/messaging in a population specific peer-to-peer encounter. Over the course of several months peer educators from a variety of CBOs were trained in behavioral theory, prevention interventions and methods of outreach to enable them to work within the multiplicity of social and sexual networks of young Black, Latino and Asia-American gay men. TEACH peer educators are trained to deliver prevention messages outside the confines of an agency's office or 9-5 business hours - instead much of the work takes place in the evenings, early morning hours, on weekends in venues as varied as street hang-outs, dance clubs, on the Internet, in neighborhood bars or at sex parties. We have learned that we need to do whatever is necessary to reach target populations- and that it is necessary and expedient to make HIV prevention appealing and relevant to younger people by embedding it in cultural and social networks. An example of an HIV prevention initiative organized by TEACH peer educators was a recent fashion show conceptualized and produced by a group of young people who created costumes, provided entertainment and delivered prevention messages, all with the support of a local community based organization. The success of the event was attributed to the "ownership" of the peer-led organizers and participants.

Dr. Keane: We have talked a lot about MSM and men of color. Are there any specific initiatives for women or for men who don't identify as gay but maybe have sex with men?

Mr. Park: We have had a lot of practice providing HIV prevention messaging to men who have sex

with men largely because that is where the epidemic started in New York City. Today we know that all communities are affected by the epidemic and this diversity poses many challenges. Gay men, women, men who have sex with men (MSM) but don't identify as gay, injecting drug users (IDU) populations all require messaging that speaks to their individual and sub-cultural identity. The Centers for Disease Control and Prevention (CDC) as well as many local programs have developed specific prevention interventions for these populations. Building on those efforts the DOHMH is investing in three major initiatives in 2005 to stem the tide of HIV infection - expanding HIV testing opportunities, enlivening condom education and distribution/availability, and working with HIV positive people to stay healthy and mitigate the transmission of HIV infection.

Mr. Hunt: I have read that for HIV positive people a key to staying healthy is monitoring your viral load and CD4 counts.

Mr. DeStefano: Yes, that's right. For someone who is HIV positive, knowing one's viral load and CD4 count are important elements in maintaining good health and monitoring drug resistance. HIV-infected people need to know that if they reliably take HIV medications their viral loads will be reduced. However, that doesn't mean that they are not infectious, one can still infect others even if they have a negative viral load. If you think about this from a public health perspective, the larger the population of HIV-infected people who are adherent to HIV treatments and are maintaining low to undetectable viral loads, the more likely we will see a lowering of the HIV community's viral load and theoretically a reduction in HIV infections. There is some data that indicates

that we may be seeing a leveling off of HIV infection in this city. Nonetheless, people are still becoming infected. Our job is to continue to design new kinds of prevention strategies like we have discussed today. We must continue to engage people in the communities where they are, be they faith-based settings, school settings, health fairs, or events such as any of the numerous cultural and ethnic parades and gatherings this city has to offer. We need to help people access HIV testing and continue to hone our educational strategies that increase the outcomes we are interested in: safer sex practices, greater awareness of the concept of harm reduction, and a diminution of behaviors indicative of "HIV burnout" and complacency.

Dr. Sederer: I think that one noteworthy development within the Department of Health and Mental Hygiene is the degree to which the office of Mental Hygiene is working closely with the Department's Bureau of HIV/AIDS Prevention and Control. This is an important collaboration because so much of what we are talking about here today is related to mental health functioning. For example, an individual's willingness or unwillingness to take care of him or herself may reflect a range of mental health problems such as depression, substance use and so on. It's important to bear that in mind when we develop prevention programs for various target populations.

*From New York City/HIV/AIDS Surveillance Statistics 2002. New York: New York City Department of Health and Mental Hygiene, 2004.

NEWS YOU CAN USE

MAJORITY OF THERAPISTS SEE DUALY DIAGNOSED PATIENTS AS "THE NORM" IN THEIR PRACTICES

Rosack (2003) reports that for the majority of attendees of the 13th annual meeting of the American Academy of Addiction Psychiatry, "dual-diagnosis patients"-specifically those with both a substance use disorder co-occurring with another Axis I mental disorder, are heavily represented in their practices. Whether it was adult or adolescent patients that were the topic of discussion, the majority of presentations at the meeting addressed the concept of dual diagnosis, proclaiming it to be 'the norm,' 'the majority of our patients,' or 'the only thing I see.'"

Rosack, J. (2003). Co-morbidity common in addicts, but integrated treatment rare. *Psychiatric News*, 38(2).

"TRIPLE DIAGNOSIS" PATIENTS ARE COMMON IN HIV CARE

Douaihy and colleagues (2003) reviewed 15 studies with a total of 5,326 subjects in order to identify "the features of substance abuse-psychiatric illness and its association with changes in antiretroviral therapy use, adherence, and HIV treatment outcomes." They use the terms "triple diagnosis" to refer to persons with substance abuse and mental illness who also have HIV or AIDS. They found that such triple diagnosis patients are wide-spread with between 10% and 87% of samples reported in the reviewed studies having HIV, psychopathology and substance abuse.

Douaihy et al. identify sepsis, pyogenic
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ON DENIAL, MOTHERHOOD

Contributed by Petra Berrios



When I was diagnosed as HIV positive in the mid-1980s, I reacted by not reacting. That is, I numbed any feelings I might have had and entered a period of denial that lasted four years.

Essentially, I continued my life, telling myself that the positive result was not mine. During the four years that it took me to accept the fact that the results were truly mine, I did not speak of it to others and did not deal with it myself. When I look back, it occurs to me that I was very much in shock. The information that I had about people who had AIDS at the time did not at all resemble who I was. After all, I did not fit into any of the "high risk groups" that were making the headlines at the time. I was not a gay man and not an intravenous drug user. The fact that I did not fit in any of the high risk groups served to reinforce my denial. Although much of what took place later was not planned out consciously, what I did was set out to prove that the positive result that I had been given was indeed erroneous. During this time I went on as if nothing had changed, but with the benefit of hindsight, I see that I began isolating myself and disconnecting slowly from family and friends. I thought on some level that I might be a walking time bomb. At some point along the way, I decided that one way to prove that I was okay was to have a baby.

In 1990, I became pregnant and went to get prenatal care. I was not asked if I wanted to be tested for HIV, since I wasn't in a high risk group, and did not share with my doctor my previous test result. During my pregnancy, I received good care and delivered my baby in December. I delivered a beautiful baby girl; it was a joyous moment in my life. Soon after however, a chain of events began unfolding with my baby. There were a lot of complications just after her birth. During this time, I felt alone and scared. I still could not

accept the fact that my daughter and I could be HIV-infected. In spite of the fears just below my consciousness, my denial was still fairly impenetrable. Around this time however, guilt and shame began plaguing me for not ever revealing to my OB-GYN doctor that I had been given a positive HIV test result in the mid 80s.

Like all new mothers, I was struggling with the immense changes that accompany giving birth. The stress of having a new baby accompanied by the shame and guilt I was struggling with sent me into a tailspin. During that period, all I could think about was death which, at the time, was the reality of AIDS. I still made no attempts to get support. At five months old, my daughter was diagnosed as being HIV positive. At that point, the reality of my own diagnosis began to hit me. I still had not sought support from anyone. Consequently, my sense of isolation intensified and I shut down almost completely for a period of two years.

My reaction to my daughter's diagnosis was the hardest thing I had ever faced. I quickly focused all my energy on my baby. As is often the case with HIV positive mothers, I put my own health in jeopardy and cared only for her. The two things that kept me going at that time were prayer and knowledge acquisition. I wanted to learn all that I could about pediatric AIDS. As for the guilt and shame, it stayed with me. I didn't share anything with others because of fear that people would blame me and I didn't think I could bear that. It was difficult getting through each day. I finally began to attend support groups for HIV positive mothers and garnered a lot of support from other mothers including those who lost their children to this HIV. During this time, I attended several funerals a month for young children. That brought home for me how important it was for me to become empowered to want to help myself and my baby live. I was sure to get her medications she needed and worked closely with our physicians. My family also became a valuable resource for us. One thing that was helpful to all of

AND LIVING WELL WITH HIV/AIDS



The Artist's Mother, 1994

us was seeing my daughter live past age five, as I had been told early on that she would probably die before that. As a result, I spoiled her early on and gave her all the things a child wants.

My daughter is now 14 years old and is in eighth grade. She has many challenges in her life. In addition to being HIV positive, she is negotiating adolescence. She has known about her status since she was about three years old and serves as a positive example of strength for her peers. There are times when she gives up and no longer wants to take medications. Usually, however, she knows that the medications have extended her life. Being so young and facing the reality of death is daunting. We received a great deal of support from the Herbert G. Birch summer family camp. There she

received support and love in a place where she was free of the stigma and discrimination of HIV disease. Perhaps most important, she was valued and accepted for who she was.

These days, a typical day starts at 6 A.M. with medications on an empty stomach followed by breakfast. It's a rigorous routine and on some mornings my daughter will say "what's the use in all this, it is not a cure." These moments break my heart, but I then change hats and my identity as an

educator moves to the fore. Our lives often feel as if we are riding a roller coaster. One of the most difficult things about HIV disease is how unpredictable it can be. When one of us becomes ill, our world gets turned upside down. During these times, I tend to disconnect from my friends and family because I am busy juggling schedules and navigating the health care system. One important aspect of all this is trying to reduce stress as much as possible. I work full time at a demanding job which involves travel and training. My employers are supportive and they are aware of my status as well as my daughter's status.

For Samantha and me, what helps most is to remember to take one day at a time. There is only so much that we are capable of handling.

We come from a culture that is not knowledgeable about HIV and we have dealt with a lot of rejection. It is important for us to get as much support as possible, especially from other people living with HIV/AIDS. People who are living with HIV/AIDS need venues to discuss the evolving nature of HIV as it impacts our growth and development, such as the ways it changes our bodies as well as the role that HIV plays in our relationships including our sexual identities. Another crucial aspect of coping with HIV/AIDS over the long haul is having a collaborative relationship with our physicians.

After two decades of living with HIV, I still have hopes for the future. I hope that the medical field continues to make gains with medications, so that the regimens have minimal side effects and interfere less with our daily lives. I also hope that we as a society will make progress toward diminishing the stigma and discrimination associated with HIV, because stigma is an additional burden that takes a toll. As an educator, I believe that knowledge and acceptance are the keys to long term survival. As for my daughter and me, we have good days and bad days. We fight fatigue and sadness but there are also many joys. Our goal is try to maintain a sense of normalcy as much as possible. The one thing that remains constant is that we are happy to have each other at the end of the day.

Petra Berrios is Deputy Director of the PWA Leadership Training Institute at Cicatelli Associates Inc. She is one of the founders of SMART University (Sisterhood Mobilized for AIDS/HIV Research and Treatment). She has been recognized locally and nationally for her work with HIV/AIDS and most recently was honored by the National Association of People with AIDS.

NEWS YOU CAN USE

bacterial infections, and hepatitis C as frequent medical complications in these patients. They state that "Drug abuse is correlated with inconsistent outpatient medical care, non-adherence to antiretroviral therapy, and a poor social support system leading to social isolation, which has also been associated with decreased adherence to antiretroviral therapy. Recent studies confirmed the importance of depression, active alcohol abuse, and injection drug use as predictors of poor adherence." But they are quick to point out that "in patients with triple diagnosis, adherence has been improved with substantial intensive efforts leading to a patient's connection to a case manager and the patient's acknowledgment of the need to accept mental health treatment and reduce substance abuse." They recommend HIV treatment be delivered in the context of multi-disciplinary treatment teams and "low threshold" services.

Douaihy, A., Jou, R., Gorske, T., Salloum, I. (2003). Triple diagnosis: Dual diagnosis and HIV disease, Part 1. *AIDS Reader*. 13(7), 331-341.

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Long-Term Living with HIV

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there, I asked him what was going on. He replied "I'm standing right here until I calm down and figure out what to do next!" After about an hour of decompression following this incident, the interview began. I share this story to illustrate the ways in which John has fiercely resisted asking for help in an effort to hold on to whatever control and independence he has in his life. I am fortunate to have known John for ten years and have observed and been inspired by his headstrong determination, creativity and compassion. Inspired by nineteenth century photography, his stylized photographic tableaux have explored themes of death, comfort, nurturing, and transcendence. As we talked, it became clear that John, a handsome, 6' 1" man, fears he will become invisible. John was raised in an English-Italian Catholic family in Connecticut. He has two siblings. His family, all having been subjects of his art, are generally quite supportive of their inspiring kinsman. In this article, I will share a few of John's insights about how he lives as a gay, sight-impaired man living with HIV for 20+ years.

Tim Hunt: John, you've mentioned that one of your greatest fears was of being diminished, of being thought of as "less-than." Would you talk about that?

John Dugdale: I was in the St. Vincent's Hospital in 1993-1994 with CMV, five bouts of pneumonia, meningitis and I also had a stroke. When I got out, my mantra became "I'll show them," meaning all those people who would no longer use me as a commercial photographer. I knew I could achieve something beautiful if given a chance. I remember making a pact with the universe that if I could keep any part of my sight and have another stretch on the planet, I would help anyone who was having difficulty due to HIV or any physical challenge. I guess the "I'll Show You" was a kind of a secret outcry which battled the challenge to my ego the stroke and sight-loss had left me. Triumph for me would show that disability would not diminish what I have to offer or who I am.

TH: What do you think has helped you cope with HIV and your resulting sight loss?

JD: I would not have been here without my photography. It has given me a sense of purpose and meaning. When I turn to the camera every other thing in my life that could appear to be wrong, disappears. Without [full] eyesight, my photographic shows have allowed me to be seen when I feared invisibility and a fading away. When I left the hospital (the last time in 1994 after a seven-month stay and having to learn to walk again), I told my mother I wanted to return to photography. She, too, seemed surprised that I would even consider it.

TH: I know how close you are with your family and how they have played a major role in your healthcare. What have you found to be particularly helpful when it comes to the Dugdale family?

JD: Being raised Catholic I was taught to mythologize, to take the stories of my life and celebrate them with rituals. Rituals are very important in my family. I was raised in such a way that grief was something that was expressed openly and theatrically, with lots of open caskets. I know many times in our culture people are whisked away to the hospital and they seem to disappear. I was exposed to deaths very early and learned to be comfortable with it, to be fascinated by the passing process. While in the hospital that year I witnessed 7 or 8 deaths in my room. People think AIDS is over. For those who experienced those years of loss and multiple deaths – we will never forget, it never goes away. It's like that trauma condition. We continue to hold on to those memories and can feel the stress every day. I miss my friends on a daily basis. I can't let go of them and don't want to. I don't have any old friends as most have died.

TH: In addition to your work what have you found to be helpful in dealing with this kind of loss?

JD: Like I told View Camera writer, Mary Ann Lynch, recently, my mother came from a strong stock of Calabrese women from the south of Italy. She taught me how to feel my feelings. Much like our ancestors, Roman soldiers would return from battle. If there were tragedies, you talked about them. You wept, you owned the thing. And in this way you conquered it.

– A Life Undiminished *An Interview with John Patrick Dugdale*



Christ Our Liberator, 1999

TH: When we have spoken of your greatest challenges you seem to gravitate to your sight loss. Where does HIV fit?

JD: I now have 465 t-cells and no virus detected for several years. My day is more full than many people without HIV. The only thing I could not erase is my CMV related sight loss and the only way to fix that is through my photographs. My goal is to not let HIV take away from my full experience

of life. Some people have difficulty with my choice of themes and have admonished me to take "happy pictures." I feel by sharing the melancholy it gets transformed into something else. My work brings that peacefulness, and I can create it for others in a two dimensional way.

TH: How do you keep pursuing your art while managing all your treatments?

JD: My baggy full of pills, 26 a day, and 20 eye-drops per day? I incorporate them, like in my coconut cream pie. If you become your illness you're done for. You can own what is happening to you rather than being a victim of it. You aren't HIV, a virus, but a person with HIV. Thinking chronic illness versus fatal virus is very important. I used to avoid the news so as not to be hypnotized by the fatal talk. Recently, I finally had a toxic reaction to my drugs. My liver enzymes went through the roof. I had to stop my Norvir. My t-cells nearly doubled rather than crashing like I expected. I feel I'm still on the vanguard like I was 20 years ago. Rather than worry about it I focus on my work and where I will get my next lens. I set my own goal to attain age 40 in the early 90s after my doctors told me a year would be what I could expect. I'm now 44 and will soon have lived with this virus for half my life. HIV related illness brings gifts to my life. The cherry on the cake is an extremely heightened awareness of life, the issue most people face later on. I'm always amazed when people see me as heroic and ask me how I do it. Everybody has the potential to be a hero if given the chance.

TH: Some have said that it can be the role of the therapist or counselor to help people find that hero within. In your work with a therapist or support group what have you found to be helpful?

JD: What matters is your journey, your path. I've learned much about this from group work I have done at Friends in Deed in lower Manhattan. The ability to accept my path and learn from it helps me avoid feeling like the victim. I believe we start passing the day we're born. I feel I've made my peace about death having accepted that I have done enough, have been a good son, brother, lover.... The day after I wrestled off the mental straight-jacket of fear, it was discovered that I had a stroke instead of instead of potentially fatal Progressive Multifocal Leukoencephalopathy (PML). Because of my HIV status, the doctors did not even check for a stroke for a month while I had seizures. I have lived through Karpos's Sarcoma (KS), pneumonia, meningitis, and have felt if someone else got better, I could too or perhaps I would be the first on the planet to lick it.

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NEWS YOU CAN USE

PHYSICIANS WILLING TO PRESCRIBE HAART TO SEVERELY MENTALLY ILL HIV PATIENTS.

Walkup and colleagues (2004) examined the use of HAART in patients with and with severe mental illness and the continuation of HAART in these samples. They compared HAART treatment in persons diagnosed as having schizophrenia or "severe affective disorder" (combining those with bipolar and major depressive disorder) to those with "no serious mental disorder." Subjects with severe mental illness were more likely than those without to have started antiretroviral medication than those without mental illness. Sixty-eight percent of schizophrenics and 75.6% of patients with severe affective disorder had initiated HAART compared to 64.3% of those without severe mental illness. However, those with severe affective disorder were less likely than schizophrenics and those without mental illness to adhere to HAART.

Walkup et al. conclude, "No evidence was found that the presence of a serious mental illness discourages physicians from initiating new antiretroviral therapy, perhaps reflecting a comparatively high level of integration of these patients into the health care system. Patients with schizophrenia are as persistent in their use of [HAART] therapy as those without a serious mental illness. Lower rates of medication compliance by those with severe affective disorder justify increased efforts to support optimal adherence."

Walkup J., Sambamoorthi U., Crystal S. (2004). Use of newer antiretroviral treatments among HIV-infected Medicaid beneficiaries with serious mental illness. *Journal of Clinical Psychiatry*, 65(9), 1180-1189.

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Long-Term Living with HIV – A Life Undiminished *An Interview with John Patrick Dugdale*

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I don't recommend people fight HIV but experience the illness so you allow it to leave your body. There is a universal need for all of us to know how to thrive before, during and after an illness. I am excited that I'm about to start my 74th or 75th show. I feel like I have more cathartic things to put on film than I ever did.

TH: After 20 years of being HIV positive, do you ever get burnout on dealing with safer-sex issues in relationships?

JD: Again, I may sound Polly-Anna-ish but I drew the line early with only dating someone HIV positive, after a few experiences with someone HIV negative who thought only a peck on the cheek should be satisfying. That didn't suit me. I stopped dating someone HIV negative because they couldn't share my experience. Now, after being asymptomatic for so long and having an undetectable viral load I have a very fulfilling relationship with someone HIV negative. You have to be imaginative and remember to have fun while being safe. I still struggle with my feelings of being attractive due to my sight. Being a burden is something I think about as well.

TH: I know you have utilized individual therapy as well. What can you tell us about this experience?

JD: My therapist helps me to feel cleansed, and sometimes challenged. She can absorb some of my pain. I can talk to her like I can't talk to my friends or family. She helped me see I am worthwhile, even to know when it is time to increase my prices. When my therapist asks a challenging question it helps me think outside the box. She's there when I don't want to be a hero or be cheerful, when I feel overwhelmed by the phone, when it doesn't ring or rings too much. I don't



Mourning Tulips, 1994

feel guilty talking to her about myself as I am with some romantic partners with which I had to hold back. She also revealed to me that she had cancer and it helped me feel deeply understood.

TH: John you've shared so much today which could be helpful to most people as they relate to your experience. Would you like to summarize?

JD: What ever you love in life, pursue it. I have memories of holy water in mom's pocketbook; my mother's, brother's, sister's hands on my body. The hurt is always there

but it can make you stronger. Don't let go of your dream. Everyone's going to die. There is no wrong time to die. I've been unconventional my whole life and now my illness has given me permission to use that to my advantage. Disability does not diminish you or your capabilities if you allow yourself to expand beyond the challenge. Remember to stay supple like a young tree and bend in the storm, rising after the storm only to be stronger.

John Dugdale was born in Connecticut in 1960 and attended New York's School of Visual Arts. Internationally known for his work as a successful photographer, he was emboldened by his HIV diagnosis in 1985 to take his commercial career in a more inspired and creative direction. John was the keynote speaker for our 2003 FAMHA conference. He resides and works in the West Village in New York City and at his farmhouse in upstate New York. He currently is represented by the Clamp Gallery on 531 West 25th Street in Manhattan and is busy preparing for his next show which opens on May 18, 2005.

Tim Hunt, LCSW, CASAC is currently Director of Mental Health Programs and the FAMHA Project at Cicatelli Associates Inc., and has a private practice in Greenwich Village, New York City.

UPCOMING EVENTS

NATIONAL HIV TESTING DAY SKILLS-BUILDING CONFERENCE

April 7 - 9, 2005

Washington, DC/Silver Spring Hilton Hotel
Silver Spring, MD

This is a two-day conference to enable networking with others from around the country who have conducted NHTD events. Participants will build skills through attending workshops. Tracks will include workshops on Campaign Strategies, Behavioral Interventions, Partnerships & Collaborations, and Evaluations.

For further information please contact:

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AIDS ALLIANCE FOR CHILDREN, YOUTH & FAMILIES 11TH ANNUAL CONFERENCE: VOICES 2005

The conference will be held at the Hyatt Regency Crystal City in Arlington, Virginia, on May 13-17, 2005.

Participants will:

- learn about state-of-the-art treatment approaches, program models, and policy options;
- exchange information about what's working in HIV/AIDS care, research, and prevention in local communities;
- learn about policy and legislation, especially reauthorization of the Ryan White CARE Act;
- explore the challenges facing women, children, youth, and families in the changing environment and epidemic; and
- connect with or strengthen your ties to other programs in the Title IV network and develop partnerships with other providers and consumers.

The following are invited to attend:

- social workers, nurses, physicians, and other health care providers
- program directors and administrators
- clinical researchers
- consumers-women, youth, and families living with and affected by HIV/AIDS, including care-giving men-and other advocates and grassroots leaders

For more information please visit the web-site at: www.aids-alliance.org/aids_alliance/voices.html, or call 202.785.3564.

ISSUES AND CHALLENGES IN CHILD AND ADOLESCENT MENTAL HEALTH

Bryn Mawr College School of Social Work and Social Research's Child and Family Well-Being Center.

April 7-8, 2005

Bryn Mawr College, Bryn Mawr, PA.

Contact: Peggy Robinson 610-520-2605;
sw-rsvp@brynmawr.edu;

Conference Link:

<http://www.brynmawr.edu/socialwork/cfwb/CconferenceDetails.shtml>

3RD ANNUAL EARLY CHILDHOOD CONFERENCE: INNOVATION IN ASSESSMENT AND INTERVENTION -

Fordham University, New York City.

April 28-29, 2005

MIDWEST ASSOCIATION OF LATINO PSYCHOLOGISTS FIRST ANNUAL MEETING

June 3, 2005

University of Illinois, Institute on Disability and Human Development

1640 W. Roosevelt Rd., Chicago, IL 60608

Chicago, Illinois,

Email Elina Manghi at elina25@uic.edu. There is no cost to attend this event (Optional dinner reception will follow. A charge will be applied. Details for reception TBA)

17TH INTERNATIONAL CONFERENCE ON THE REDUCTION OF DRUG RELATED HARM

Abstract Deadline: 3 October 2005, 1700 PST

Location: Vancouver, Canada

Conference Dates: 30 April - 4 May 2006

LONG-TERM SURVIVORS OF HIV IN THE MR/DD COMMUNITY:

Putting a New Face on an Old Problem

Submitted by Donna Smith, B.A.
and Bobra Fyne, LMSW

Question: "How do you feel about living with HIV?"

Answer: "Miserable...I don't want to live with it — I want to get over it."

This sentiment is from a person in the MR/DD community who is HIV-infected. People living with HIV/AIDS have many faces. Unfortunately, the faces of people with MR/DD who are also HIV-infected are faces that are not frequently recognized or considered. Their faces are in fact often overlooked. People living with mental retardation and other developmental disabilities (MR/DD) are indeed among those who are long term survivors of HIV infection. Given the sustained impact of managing HIV disease over the long haul, lack of discussion about the special needs of HIV-infected individuals with MR/DD adds another layer of complication.

G is an African-American male who has mild mental retardation. He is bright, articulate and has been living with HIV for almost ten years. G contracted HIV through unprotected sexual intercourse with an infected partner who was unaware of her status at the time. Since he found out he was HIV positive, he reports feeling "miserable". He states that he hates the fact that he has HIV and wants to "get over it." G doesn't speak to people about living with HIV because he does not want people to know that he has it.

People with MR/DD face a great deal of everyday scrutiny in their communities. Given this heightened level of scrutiny and the attendant high levels of embarrassment that may accompany it, G's feeling that he does not want to speak about "it" is less surprising. Coupled with living with a virus that many people refer to as "The Beast", or "The Monster," it becomes quite clear that finding people, let alone a person to confide in, becomes an extremely daunting task for someone like G. Their often able-bodied counterparts, long term survivors without MR/DD,

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NEWS YOU CAN USE

A NEW JOURNAL OF DUAL DIAGNOSIS BEGAN PUBLICA- TION IN 2004!

According to the Editor of the new journal, Peter F. Buckley, MD, "There is no specialized journal on dual diagnosis, encompassing basic mechanisms, clinical and therapeutic aspects of substance abuse comorbidity with mental disorders." The journal is intended for clinicians, research neuroscientists, mental health service researchers, and health service administrators as well as junior colleagues in training. It will help the reader to stay current with trends in research, best practices in treatment, case studies, etc. The Journal of Dual Diagnosis: Research and Practice in Substance Abuse Co-morbidity, Peter F. Buckley, MD, Editor can be found at:

<http://www.haworthpress.com/store/product.asp?sku=J374>

RESOURCES:

Addiction Abstracts:
<http://www.tandf.co.uk/addiction-abs/>

Dual Diagnosis Website:
<http://users.erols.com/ksciacca/>

LONG TERM SURVIVORS OF HIV IN THE MR/DD COMMUNITY: *Putting a New Face on an Old Problem*

may be less likely to have histories of long-term mental, emotional and physical abuse as well as the persistent social stigma that people with MR/DD deal with. While they confront some of the same complex problems, they are less likely to have to combat destructive stereotypes in addition to living with an incurable virus.

In a very general sense it is already difficult for people with MR/DD to gain access to others like themselves—we see this in many facets of their lives. Many people with MR/DD operate in very small social circles. They may live in group homes or at home with their parents or other legal guardian and go to a day program, but chances are they are interacting with the same people everyday. In many cases a daily routine is standard and the ability to interact with peers on a social level or meet new people is rare or non-existent. Even with the best of intentions people with MR/DD are quite often the victims of over-protection for the sake of health and safety. Their history marks them as vulnerable to abuse and exploitation and statistics substantiate the claim. The results of this abuse and exploitation are far-reaching and will be explored next.

People with MR/DD are often denied the basic rights most people demand as adults such as making decisions about where they live, who they live with, who their friends are, what to do with their free time, and even to have an intimate relationship with someone else. These methods of over-protection often also exclude people with MR/DD from obtaining the necessary education to make informed decisions about their body and sexual relationships. That is often the reason why acceptance in the MR/DD community entails having unprotected sex with a typically abled individual to feel more "normal." The ability to negotiate condom use and establish boundaries is a skill that many people with MR/DD often lack because of a prevailing thought that either, they aren't sexually active, don't want to be sexually active, or are incapable of making that determination for themselves. So given this state of being, people with MR/DD who may also be long term survivors of HIV/AIDS not only have the obstacle of accessing needed information and supports, but also gaining access to others like themselves in order to enrich their quality of life. This is G's dilemma.

"There's no one to talk to" is a frequent problem that is verbalized. Support groups remain a

staple for many people infected with and affected by HIV and AIDS. The best research evidence available overwhelmingly supports that successful healing comes about in an environment characterized by trust, warmth, empathic understanding and acceptance. For G, finding a group where he will be accepted as a man with mental retardation, let alone one who is living with HIV, has proved difficult enough to keep him from the search.

Learning more about HIV/AIDS has been a point of interest for G. He now knows that "HIV is the virus that turns into AIDS" and that "an important way to protect yourself from getting HIV is to use condoms when having sex."

For those of us who continually struggle with how best to educate people with MR/DD about HIV/AIDS prevention, it would do us well to note that these two points of interest can serve as an outline for a very successful training curriculum.

Given that people with MR/DD continue to be diagnosed with HIV/AIDS, there is a greater need for educational initiatives that target this at-risk population. Development of curricula that is accurate, interactive, yet simple to use is key to teaching people with MR/DD about HIV/AIDS, and vital to providing a long-term solution to HIV infection within the MR/DD community.

We as educators and counselors must also endeavor to learn as much as we can about those people in the MR/DD community who are long term survivors of HIV/AIDS. This can entail, but is not limited to, assessing what services are currently available to those individuals, creating services that are tailored to their specific needs and wants, and educating people with MR/DD who are long term survivors about re-infection, STI's and healthy lifestyles. In addition, development of programs that assist these consumers with optimal adherence to medication protocols is also extremely important.

At YAI/NIPD we have always believed that prevention efforts for this population must have an individual perspective. We, as educators and counselors, must be able to recognize that continued education and support for people like G who are long term survivors is a vital part of ensuring quality of life. It is truly up to us to help G and others like him see that there is life after being diagnosed with HIV.

For more information about YAI/NIPD services contact Donna Smith at 212-273-6430.

A Letter from the Editor

(continued from page 1)

HIV/AIDS. The study examined a control group of healthy persons with CD4 counts between 150 and 500mm³ without symptomatic AIDS and compared them with two other groups. One comparison group was a group of long term survivors defined as persons who had symptom-defined AIDS for at least four years before beginning protease inhibitor treatment. A second comparison group included healthy persons with very low CD4 counts who had remained symptom free for at least nine months before beginning protease inhibitor treatment. The variables that emerged as distinguishing the long term survivors from the other groups were the role of religion and spirituality in coping, the presence of a collaborative relationship with one's physician and having an optimistic outlook. The nature of such a collaborative relationship with the physician was described as one in which the consumer felt that they and the physician were partners in decision-making around disease management and where discussion was actively encouraged, especially where medications are involved. Spirituality also emerged as a strong and effective coping response. On a scale that detailed the role of religion and spirituality, long term survivors reported feeling that they had faith, attended services, meditated or prayed regularly and had a sense of compassion for others.

We are honored to have submissions by two persons who maintain high profiles in the PWHA community. John Dugdale sat down with me to discuss the ways in which HIV has impacted his health, his life and his art. Mr. Dugdale's disease progression has directly affected his vision which, in relation to his photography, has been one of the foundations of his creativity. How he has integrated the many losses he has experienced and made adaptations to move beyond potential obstacles are some of the things we discussed during the course of his interview. We also appreciate the generous contribution of John's photographs for this issue. Secondly, Petra Berrios has written an article about her own 20 year struggle with HIV from the perspective of mother, educator and consumer. Ms. Berrios is the Deputy Director of the PWA Leadership Training Institute, housed at Cicatelli Associates Inc. and funded by the New York State Department of Health's AIDS Institute.

Thank you to our regular contributors. Lloyd Sederer, M.D. Executive Deputy Commissioner, Division of Mental Hygiene at the New York City Department of Health and Mental Hygiene. In this issue, we continue the conversation that we began in the Fall of 2004 that addressed the ways in which HIV prevention programs must change as HIV epidemiology transitions with time. We thank Dr. Sederer and his colleagues

at the Department of Health and Mental Hygiene for their insights. Finally, we wish to thank Bobra Fyne at YAI for her continuing contributions to the newsletter.

The FAMHA newsletter is a quarterly publication which seeks to provide education and information on topics in mental health for providers who serve people with HIV/AIDS (PWHAs). It is funded by the New York City Department of Health and Mental Hygiene. In our next issue, we will focus on the topic of crystal methamphetamine and its role in spreading HIV disease. We hope you enjoy reading the Winter 2004-2005 edition of the FAMHA newsletter. Feedback and suggestions on how we can make the newsletter more useful are welcome. Please send comments, questions and correspondence to tim@cicatelli.org.

Sincerely,



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THE FIVE BOROUGH AIDS MENTAL HEALTH ALLIANCE (FAMHA) is an educational project managed by Cicatelli Associates Inc. (CAI) and funded by the New York City Department of Health and Mental Hygiene. The project's mission is to provide training and technical assistance on subjects related to HIV/AIDS mental health including such topics as assessment and treatment of co-occurring mental health and substance use problems. A wide array of training and technical assistance programs is available for agencies providing services to people living with HIV/AIDS. Readers may request programs by completing the application for training form on the back cover of the newsletter and returning it to CAI. For further information, please contact behavioralhealth@cicatelli.org.



5 FAMHA Service Needs Assessment

To request a FAMHA program for your agency/organization, complete the following needs assessment and submit it by mail or fax to:

Cicatelli Associates Inc. • 505 Eighth Avenue, Suite 1601 • New York, NY 10018
phone: (212) 594-7741 • fax: (212) 629-3321 • e-mail: tim@ciatelli.org

Name _____

Agency/Organization _____

Address _____

City _____ State _____ Zip _____

Phone _____ Fax _____ E-mail _____

Desired Training Day(s)/Time(s) _____ Anticipated Audience Size _____

Attending Disciplines

(check all that apply)

- Clergy
- Counseling
- Marriage/Family Therapy
- Medicine
- Nursing
- Psychiatry
- Psychology
- Social Work
- Case Management
- Other (please identify): _____

Desired Training Format

(check all that apply)

- Grand Rounds
- Interactive Small Group
- Lecture

Desired Training Topic

(check all that apply)

- Treatment Update/Adherence Issues
- Harm Reduction Strategies
- Management for Active Substance Abusers

- Case Management for HIV-Infected Clients
- Issues Relevant to Culturally Competent Service Delivery
- Family-Focused Mental Health Services
- HIV Pre/Post-Test Counseling
- Building HIV Support Groups
- Stress Management
- Boundaries and Countertransference
- Suicide Assessment and Prevention

Technical Assistance:

Face-to-Face Skill Building/ Consultation with Agencies

(check all that apply)

- Making Referrals
- Cultural Diversity
- Behavior Change Models
- Human Resource Development
- Infrastructure Building
- Managed Care
- Implementation of Risk Reduction Groups in MICA Programming

- Special Needs Plans
- Condom Procurement for Clients on Medicaid
- Stress Reduction (Support Group Facilitation)
- Case Conference