

LAP NOTES

LESBIAN AIDS PROJECT AT GMHC

ISSUE NO. 7 SUMMER 1999

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THE RESEARCH ISSUE

GMHC Roundtable HIV-Positive Lesbian Research Interview

This interview was done with three HIV+ lesbians. We are not using anyone's name in the interview, because people were worried about the impact it could have on them, their kids or on the research studies they are participating in.

So, is it important to research lesbians that are HIV+?

LESBIAN #1: I think it's important if they're going to find out something new, something different and they're not just asking questions that get them off. I mean, like if there is HIV transmission woman to woman, that would really interest me. Some people say yes, some people say no, some people say they don't know. I think maybe there are questions that can be helpful for lesbians that are coming out.

There alot of different reacons to be a part of any research project, right? So what were some of all of your reasons to participate?

LESBIAN # 1: At the time of the study I first got involved with, I heard about it

through word of mouth, and I was alone and I had to feed my kids, and if they were offering a study that gave money, I went in there blindly and it got me a few meals, you know, during the week. It was good for me, that's why I did it.

LESBIAN # 2: You know, I respect your reason and I can relate to that because, you know, as a mother, we'd do anything to feed our kids, and we've all been there. But now that I'm living in a sober state of mind, now that I'm feeling in control, I just couldn't do it.

Have you ever felt like the studies were the only way you could get medical care?

LESBIAN # 3: Yes.

LESBIAN # 1: Yes. The study I'm in, I go there twice a year and I get money and I get an exam. The good thing about it is that my PAP smears are normal, because I'm concerned about that. But underneath, you know, I started going for the money.

Given that part of where alot of research happens is in vulnerable communities, what do you think women and people of color and poor people need to do to see that the

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Notes from LAP



by Amber Hollibaugh, Guest Editor

I have just finished re-reading all of the old LAP Notes that came before this one, all six of them, and I am struck by the continuing power of the stories which filled their pages and of what they document; stories by HIV+ lesbians and their partners, their lovers, their families and their friends.

I am moved again by what these newsletters chronicle through the nearly six years they have been printed, the accounts they record of breaking through the invisibility and shame of being a woman who loves other woman who is also living with AIDS and the tales of being a friend, partner or family member of a lesbian woman living with HIV. These past newsletters detail the incredible bravery, the humor and the loss we have suffered as a community. They are filled with articles by activists and care givers — both lesbian and straight — who have cared enough to write the pieces they've needed but could never find. And the old newsletters are full of the humor and the bravery of lesbians living, confronting, getting tired of and surviving their struggle with HIV and AIDS. Sadly, they also chronicle some of our losses and our memories of the women we have worked with and loved who have passed. Finally, the stories on those pages are an important part of a much bigger picture that is still to be told in this battle... against an epidemic called AIDS and the fight against the fear and shame of being a lesbian — and of what happens when they are combined. So again, I welcome you to the seventh issue of LAP Notes.

It's been awhile since our last issue of LAP Notes and once again much has

changed at GMHC and at LAP. GMHC, like nearly every other AIDS agency in this time period, has been going through a two year struggle to cut back and restructure in a tightening economic crunch. It has often been scary and difficult on us all. Though we are not quite out of the woods yet, the good news is that LAP has survived and is growing — with new staff women and new HIV+ lesbian peers — and we continue to serve lesbians and other women who partner with women who are HIV+ or affected by AIDS. We also continue to be a vibrant part of the larger women's services department at GMHC.

There's a lot of news at LAP... First and foremost, there is a new Coordinator of the Lesbian AIDS Project, Tia-Nicole Leak and LAP has a new Outreach Coordinator, Michele Fitzsimmons. As well, there are six new LAP peer workers on board. LAP and the Women and Family Services department staff and volunteers continues to provide supportive structures, groups, counseling services, acupuncture, women and lesbian-specific events and forums for at-risk and positive women who have sex with women. We also continue helping HIV+ or at-risk lesbians access all the rest of GMHC's services which are available to them when they become clients here. At one time I was the director of LAP, now I am pleased to say that I am here as a consultant working to bring you this new issue of LAP Notes.

This edition of LAP Notes focuses on the concerns surrounding our need for Lesbian-specific research — of what we have as lesbians, (very little), and what we need (everything), and all the issues in between — especially any

LAP NOTES

EDITOR
Amber Hollibaugh

DESIGN
Stephen de Francesco

WOMEN & FAMILY
SERVICES DIRECTOR
Talata Reeves

LAP COORDINATOR
Tia-Nicole Leak

LAP OUTREACH
COORDINATOR
Michele Fitzsimmons

CLINICAL
SUPERVISOR
Selma Torres

LAP LESBIAN PEER
LEADERSHIP PROJECT
Joyce Mazyck
Lillian Nieves
Theresa Rogers
Jeanette Williams
Cheryl Hall
Lisa Pabon

LAP-NDRI LESBIAN
PEER OUTREACH
WORKER
Doralisa Goita

LAP INTERN
Lisa Magged

VOLUNTEERS
Donna Aceto
House of Moshood

research being done about Lesbians and HIV. And while this issue of LAP tries to give an overview of WSW (women-who-have-sex-with-women) research, and specifically some of the lesbian specific HIV research projects we know about, we are also publishing a roundtable interview with HIV+ lesbians about their experiences being the *focus* of research — something too often missing when there is a discussion of our research needs as a community. We also have an article by Marj Plumb about a new IOM report which was just released by the federal government about lesbian health research needs and we are reprinting the recommendations which came from that report. A lesbian researcher, P. Clay Stevens, has written a piece about doing research in marginal or hard to identify communities. And Beck Young reports on the first and, to date, only HIV+ WSW ethnography currently being done, which received federal funding. This issue of LAP also tells you how to access a lesbian health network if you are thinking about incorporating or doing any lesbian-specific health research as a part of your organizations work.

Also in this issue we celebrate the lesbian wedding of Linda Ellis, a woman who used to be a LAP peer leader and who is now a staff person in the GMHC women's department with her lover, Tony. We also congratulate many of the former LAP peer staffers who have moved on to new and exciting jobs. And, sadly, we have memorials for two of the women we've lost since we last went to print.

Finally, it is important to us at LAP to recognize the global impact of HIV and AIDS, especially as it affects women, some of whom are lesbians. LAP

has always received letters from women in many, many different countries around the world, seeking hard to find information or telling us their stories. Women internationally represent nearly 40% of all known cases of HIV and AIDS and our numbers continue to spiral. As well, the risks of HIV transmission to our babies through pregnancy or breast feeding and the overall impact of HIV and AIDS on our children and families is an international crisis that is worsening daily. Not only our risk for HIV but the lack of funding for treatments globally, leave women, their families and partners without the medical hope that these new treatments represent in the United States. LAP and Women and Family Services at GMHC know that part of our role of advocating for women around HIV and AIDS means advocating for *all* women at risk for HIV, everywhere. At LAP we know how devastating AIDS can be, wherever it happens and whomever it happens to. And we know first hand the effects of invisibility for women. That's why we don't intend to forget women in all the nations around the world who are struggling, surviving and confronting AIDS. For LAP, it is all our fight, regardless of the country in which we live or the gender of the person we are sleeping with.

This is a strong issue and one to again be proud of. I hope you find it both good to read and useful to you at the same time. LAP wants your comments and your feed back too, so write us — tell us what you're doing, thinking, needing, discovering. Our power as a community of lesbians committed to surviving and thriving in the face of AIDS is built on the strength, the visibility and the dialogue between us, a dialogue which educates and informs us all.

**This edition of
LAP Notes focuses
on the concerns
surrounding our
need for Lesbian-
specific research —
of what we have
as lesbians, (very
little), and what we
need (everything),
and all the issues in
between...**

An Update About Some Former LAP Leadership Peers...

One of LAP's goals when it created the Lesbian Leadership Peer Project was to serve as a new starting point for lesbians and wsw women who were mostly HIV+ or deeply affected by AIDS so that they could get back into the work force, go to college or both if they wanted. We hoped that LAP would provide a way for lesbians to step forward, use their expertise around HIV/AIDS and get new skills and training so that if they wanted they could do full time paid, meaningful work. It has been four years since the program began and we want to report on the success of many of those early LAP Peers and let you know what they're doing now.

Rochelle Burroughs was a part of the first group of women peers which began the LAP Leadership Project. Rochelle now works full time counseling women at risk for HIV at Lincoln Hospital.

Doralisa Goitia was also in that first group of lesbian peers at LAP. She is again working with LAP in their partnership with NDRI. She is the HIV+ lesbian outreach worker for positive and at-risk WSW's for the WSW research grant being carried out at NDRI, while she continues to raise her daughter and son. Doralisa will go back to college in the fall of 1999.

Iris Maldonado has become the Women's Outreach Coordinator at Iris House, a service agency for positive women in New York City and she continues to raise her teen-age daughter, who has become a high school HIV/AIDS peer educator for other young people.

Linda Ellis has become a Harm Reduction Counselor in the Women and Family Services department at GMHC. If you want to know more about Linda, you can read about her in another part of this issue of LAP Notes.



Jackie Barnes has become a Community Follow-Up Worker in Intensive Case Management at GMHC. At nearly the same time as she became a peer worker at LAP, she decided to go back to college. She will complete college and graduate with a BA in six months.

A.J. Wright is now a clinical Counselor at SuCasa in NYC. She went back to college when she was a LAP Peer and got her BA. We are thrilled to report that this July she will receive her Masters Degree.



And An Introduction To Some New Faces...

And finally, we are pleased to report that **Luz Hernandez** has moved on and become a peer at Body Positive. **Angelique Abuqattam** is now working full time at ADAPT and **Debra Green Gordon** is working full time at Our House.

The new LAP Peers are (back row, left to right) **Joyce Mazyck, Cheryl Hall, Jeanette Williams,** and **Doralisa Goita**, NDRI-LAP Peer Outreach Worker; (front row, left to right) **Lisa Pabon, Lillian Nieves,** and **Theresa Rogers.**



Tia-Nicole Leak became the Coordinator of the Lesbian AIDS Project in January of this year. Prior to joining the Women and Family Services department of GMHC she was a Trainer within the agency's Training department. She has nearly nine years experience in community organizing, advocacy, training and staff development, having worked in Mayor David Dinkins' administration with Dr. Marjorie Hill on the "Children of the Rainbow" curriculum, and at Hetrick-Martin Institute where she created a Peer Education Program and trained lesbian, gay, bisexual and transgendered youth in lobbying and community organizing.



Michele Fitzsimmons was recently promoted to Outreach Coordinator. Before joining LAP in May 1998, she worked as both a Financial and a Health Care Advocate in GMHC's Client Advocacy department. She has over seven years experience in HIV/AIDS, starting in the Women's Project, a special unit of the Division of AIDS Services.



If a Lesbian does it, is it Lesbian research?

(Or, as my grandmother said, "If you don't know Who, What, When, Where, Why, and How, you don't know nothin'!")

by P. Clay Stevens

EDITOR'S NOTE:

If you are a woman who is HIV+ or at risk and you are thinking about getting involved in a study or if you are a concerned researcher who may be working in a community where you have little life experience, this piece for LAP Notes may have special relevance for you. The WHO, WHAT, WHEN, WHERE, WHY & HOW sections clearly lay out what you need to assess before you get involved in a study or, if you are a researcher, before you begin working in a vulnerable communities.

Research, particularly in this age of HIV/AIDS, can be a necessary evil or a glorious pursuit. The former can be intrusive and disruptive eating up time and dollars without appreciable return. The latter sounds great, for example, hunting for a cure for breast cancer or HIV, but can be equally frustrating along the way. Even "good" research is often tedious, exacting, and exhausting to both researchers and those being studied.

"Lesbian" research is no different. For example, to receive resources to provide HIV prevention services to lesbians, an individual, group or agency must prove that [1] there are enough infected lesbians to warrant concern, that [2] services that can be offered will be used by lesbians, and that the service works — lesbians who use it will stay HIV negative. This is often made more difficult as the funding agencies that require this proof are often the very agencies that, through their regulations and/or methodologies, may contribute to the invisibility

of lesbians among those who are or may become at risk for HIV.

Good research begins with a good question. While the term "good" is subjective and may differ from woman to woman, there is general agreement that frivolous, unnecessarily dangerous (to participant, researcher, or the community), and/or exploitative research is to be avoided both ethically and scientifically. Said another way: garbage in - garbage out.

Definitions of scientific inquiry state that scientific knowledge is gained step-by-step in a logical and obvious order. Each new question grows out of the last question asked and answered. A good question can lead to good findings which, when applied, can result in a good outcome.

The research process can be broken down as follows:

WHAT: What is the scientific question? Is it important? Is it the right question to ask at this particular point in time? Can the question be pursued in an ethical manner? Can it be answered without undue risk to participants?

WHY: Who or what will benefit from the research effort? Does it solve a problem or intervene in a situation that causes harm? Will the study participants benefit or will it only benefit others at a later date? Who has asked for or called for a solution? Do the potential benefits outweigh the potential or actual risks? Who has made that judgement?

WHO: The Researcher: The researcher(s) must understand the community in

which they work. If not a member of the group or community being studied, they must take particular care to be sensitive to and respectful of the community. The researchers must be willing and able to include indigenous members of the community or group in the planning, recruitment, work, analysis, and publication/application stages of the project. The community from which the participants are drawn should directly benefit from the presence of the research effort either in capacity building or in infrastructure development.

WHO: The Participants: Participants must be volunteers who, after learning the benefits and potential risks of participation, agree to become involved. While the participant is obligated, under this agreement, to follow instructions, regimes, etc., at any point the participant must be able to withdraw from the study without penalty or loss of services and care.

WHAT: What will happen during the actual study? Are there questions to be asked? Will blood or other body fluids and/or tissues be sampled? Will the participant be apart from family and friends for a period of time? If so, how and for how long? Is there risk associated with the required study activities? Will the participants be permanently changed or affected by the experience of participation?

HOW: The Project: How will the activities of the study be carried out? Who will do the required activities? How were these individuals trained? Are they

being monitored during the study to assure that each of them behaves in a similar manner during the study activities? Are there any machines, instruments, or tools involved in the study? Are they safe and how are they maintained?

WHEN: At what point in time does the study begin and for how long does it last? Will the time involved interfere with the regular activities of the participants? If yes, is the participant willing to make these changes and/or being compensated for time and inconvenience?

WHERE: Does the participant come to the study site or vice versa? Is the site convenient, safe, comfortable, and confidential? Does being seen coming to the site or being visited by the study staff reveal anything private or confidential

about the participant to others in the community?

HOW: The results: How will the results be used? By whom for whom? Will the results be published? By whom? Will the study results be presented to the participants? Before or after public release of the findings? Will the individual participant's outcomes be made available to the participant? If not, why not? Who will "own" the research findings? Who will have final approval on publication?

Lesbian health and HIV research can provide information critical to our daily lives. Research of all types, social, behavioral, laboratory, and clinical, can help us to understand ourselves and to advocate for our needs. The outcomes can also show us what we have in common with others. Lastly, research can

contribute to the education of others outside our communities. To accomplish effective research social, behavioral, and clinical scientists typically need access to persons within the Lesbian community and to the organizations that serve them. Not all researchers respect the integrity or experience of their "subjects" nor of the organizations that assist them. It is vitally important that we develop standards for research in our communities, that our agencies be recognized and compensated for their contributions to academic and governmental research, and that researchers from within our communities have access to training, collaboration, funding and resources to support high quality research efforts.

P. Clay Stephens is a Research Scientist. Her work on "HIV-1 Survival in Syringes" has just been published in the January issue of Acquired Immune Deficiency Syndrome and Human Retrovirology. She is currently working on an article on HIV viral load in cervicovaginal and menstrual fluids.

Genital Human Papillomavirus Infection in Women Who Have Sex With Women

Journal of Infectious Diseases Online (12/98) Vol. 178, No. 6, P. 1604; Marrazzo, Jeanne M.; Koutsky, Laura A.; Stine, Kathleen L.; et al.

Researchers from the University of Washington and elsewhere report that genital infection with human papillomavirus (HPV) and squamous intraepithelial lesions are common among women who have sex with women. Using polymerase chain reaction detection of HPV DNA and the prevalence of HPV-6 and -16 antibodies, the researchers studied 149 women who have sex with women and found that 30 percent of the subjects had HPV DNA. Of these women, one-fifth showed type 31/33/35/39, 18 percent had type 16,

and 2 percent showed type 6/11. Nineteen percent of 21 women who reported no prior sex with men had HPV DNA, while 14 percent had squamous intraepithelial lesions. A total of 47 percent of all subjects were seropositive for HPV-16 and 62 percent were positive for HPV-6. The researchers note that current smoking was associated with detectable HPV DNA and that the suboptimal Pap smear screening among the participants who reported no prior sex with men warrants further investigation among a larger study group.

WHY ALL THE HOOPLA?

by Marj Plumb, MNA

Those concerned about the lack of attention paid to lesbian health concerns by the medical establishment often hear one constant refrain from research funders, medical journal editors, and public health authorities, “unless you have research that proves the importance of lesbian health issues we won’t pay attention to you.” The cruel circle this response places us in has frustrated the lesbian health community for decades: without funding for research we can’t do quality research, without quality research we can’t get published in medical journals, without being published in medical journals we can’t convince health experts that a health need exists, without proving to health experts that a health need exists you can’t get funding for research, and so on...” And then came Dr. Vivian Pinn, the Director of the Office of Research on Women’s Health at the National Institutes of Health (NIH) — a heterosexual woman, she was an unlikely leader in the lesbian health movement. But her efforts to deal with the lack of credible research on lesbian health has done more to advance the lesbian health movement than anyone I can think of.

Through Dr. Pinn’s efforts, the NIH and the Centers for Disease Control and Prevention (CDC) funded the Institute of Medicine (IOM) to write a report on lesbian health research priorities which was released in January 1999. As a significant institute within the National Academy of Sciences, the IOM is perhaps the most highly regarded voice in medicine. Like the Supreme Court, which interprets the constitution and

laws, the IOM interprets science...and people listen. It was through the constant advocacy of lesbian (and some bisexual and transgender) health activists throughout the country that urged Dr. Pinn to find a way to address lesbian health research: And, it was her insight into the health establishment, and her knowledge that nothing short of an IOM report would make medical providers and researchers pay attention, which brings us to this historic moment.

The IOM report provides an extensive review of much of the health research that has been done concerning women who have sex with other women. It addresses the methodological and ethical issues inherent in conducting research on this population, and it suggests avenues for further research. Why all the hoopla? A published report from the IOM on lesbian health will immediately assist lesbian health researchers to find funding for quality research, publish in medical journals, and receive support and validation from the medical and research institutions they work in. The IOM report legitimizes the field of lesbian health in ways we have not seen to this point. In every field of lesbian health, from HIV to Cancer, there have been questions raised by our community about our risks, the impact of disease on our lives and communities, and about barriers to prevention, screening, and treatment. Now, with the IOM report, we may be able to get the funding to do the research to answer those questions.

But as the report is distributed throughout the research community it is also expected that individuals who have not previously researched lesbians will become interested, especially if there is money available for researching this population of women. This will pose an interesting problem for the lesbian community which has not, for the most part,

been actively involved in developing and managing research studies. Is the lesbian community ready? Do we have the researchers with the expertise and the credentials to compete for research grants? Is it safe enough in their institutions for researchers to be “out” and to participate in lesbian-specific research? Does the mainstream research community truly understand the importance of confidentiality and informed consent when researching lesbian and bisexual women? Do we have a community that understands the importance of this research and the importance of being a fully educated partner in the research process? If not, we risk being left on the sidelines, watching a process that will define us without us.

Research, even well-funded research, can be harmful to the very populations it seeks to assist. Much of the research already completed on the lesbian, gay, bisexual and transgender communities has been inadequate to describe how truly diverse we are. Some of the research is also, inadvertently and sometimes overtly, used to further stigmatize us. An example of this problem is the market research that declares high disposable income among gays, which is biased due to their reliance on gay readerships of glossy publications, has been used within the courts to challenge gay civil rights laws.¹ The same market research has then been relied upon to justify inadequate sampling of lesbian health research. For example, a researcher in Chicago, sampling lesbian and bisexual women for a study on alcohol consumption, reported a significantly high average income among her study population but justified it by saying that “that is what is reported for this population.”²

It is indeed very difficult to research invisible and stigmatized individuals.

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Lesbian Health Report

CURRENT ASSESSMENT & DIRECTIONS FOR THE FUTURE

Andrea L. Solarz, Editor
Committee on Lesbian Health Research
Priorities, Institute of Medicine

Editor's Note: This article is selected excerpts from the Lesbian Health report published by the Institute of Medicine. For a complete copy of the Executive Summary or the complete report contact the National Academy Press at 800-624-6242 or visit the NAP's online bookstore at www.nap.edu.

Despite growing attention to research on women's health over the past decade, the health problems of some subgroups of women have continued to receive relatively little attention. Lesbians are one such subgroup. Although the body of research on lesbian health is growing, much of the research to date has methodological limitations, such as the lack of appropriate comparison groups, that make it difficult to draw clear conclusions about the health status and health risks of this group of women.

The Institute of Medicine (IOM) Committee on Lesbian Health Research Priorities was convened in July 1997 to:

1. assess the strength of the science base regarding the physical and mental health of lesbians,
2. review the methodological challenges involved in conducting research on lesbian health, and
3. suggest areas for research attention.

The study was funded by the National Institutes of Health (NIH) Office of Research on Women's Health, with the Centers for Disease Control and Prevention (CDC) also contributing funding through the NIH.

A primary charge of the committee was to organize and convene an invitational workshop to examine these issues. The workshop, held in October 1997, focused on the challenges involved in designing and conducting research on lesbian health, some of the contextual issues that make it more difficult to conduct such research, and lesbians' risk for particular health conditions including cancer, mental health problems, substance abuse, HIV infection, and sexually transmitted diseases. Lesbians' use of and access to health care services were also discussed. The workshop involved 21 invited speakers, public testimony from more than a dozen presenters, and approximately 50 interested members of the public who also participated in the discussion.

Conclusions

Following its broad review of what is known about lesbian health and the factors that influence it, the committee reached three major conclusions:

Conclusion 1: Additional data are required to determine if lesbians may be at higher risk for certain health problems. Further research is needed to determine the absolute and relative magnitudes of such risk and to better understand the risk and protective factors that influence lesbian health.

Conclusion 2: There are significant barriers to conducting research on lesbian health, including lack of funding, which

have limited the development of more sophisticated studies, data analysis, and the publication of results.

Conclusion 3: Research on lesbian health, especially the development of more sophisticated methodologies to conduct such research, will help advance scientific knowledge that is also of benefit to other population groups, including rare or hard-to-identify population subgroups and women in general.

The committee identified several gaps and priorities for additional research, which follow:

Research Gaps and Priorities

Priority 1: Research is needed to better understand the physical and mental health status of lesbians and to determine whether there are health problems for which lesbians are at higher risk as well as conditions for which protective factors operate to reduce risk to health of lesbians. There is some evidence that lesbians may be at heightened risk for some health problems. There are, however, large gaps in the knowledge about lesbian health, and the population-based data needed to determine their relative health risks are not available. It is critical that such research include consideration of the impact of socioeconomic and cultural factors on the health of lesbians.

Priority 2: Research is needed to better understand how to define sexual orientation in general and lesbian sexual orientation in particular and to better understand the diversity of the lesbian population. Definitions of lesbian samples in research studies have varied wide-

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Annette Rodriguez-Dorsey 1950-1999

For Annette

Power of example
that moved so many of us
to stay sober
to crave health
to love
to do the right thing for ourselves

calm, strong
always holding
the perspective
deep smile
and convictions

quiet and firm in her ways
she could awaken the fire in us
and help us move forward

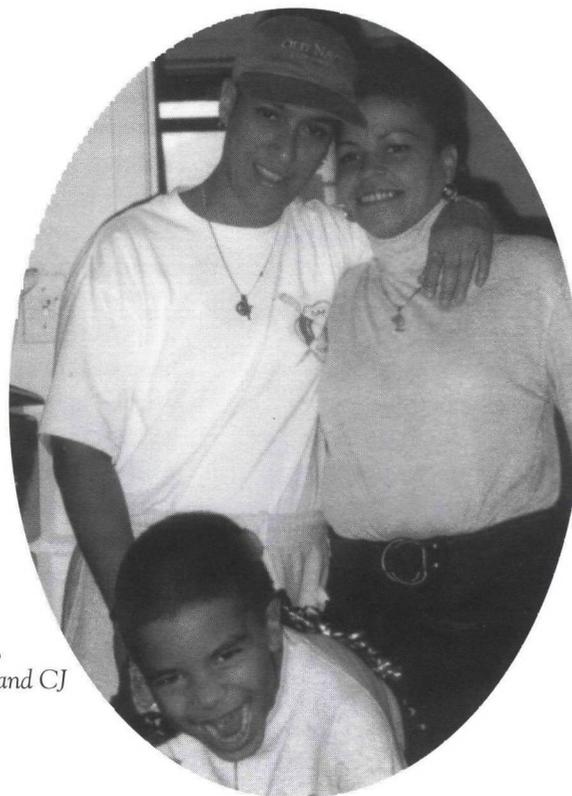
Mother of the House of Moshood
counselor, guide, friend, protector, we miss you
we honor you
smile us into the future
forever.

—Ana Oliveira



© Donna Aceto

Alma Maritza Cortez 1957-1999



Maritza,
Leticia and CJ

For Maritiza

So here we are. Gathered here because Maritza was special to each and every one of us. For having the opportunity to know and love her, I will be eternally grateful. She was my first out relationship, she was such a dyke. The companionship, the affection, the passion, was incomparable to anything I had ever experienced. She made me feel beautiful. Mostly she gave me strength.

She changed the person that I am. I know that she contributed to who CJ, my six year old son is and who he will be in the future. She was an excellent Mom to him. She taught him about AIDS, how people survive with countless odds against them. In doing this, she taught him compassion. She taught him diversity—how this world is filled with people different that the ways we may be, but how to respect others even if they are different from ourselves. He loves and misses her so.

Yet through CJ, I am learning how to accept my loss. He, like most children, are so flexible. They accept Life on lifes terms. He is so smart too. He believes she will live within us through the love that we shared and through the memories that we made together. He says he will not be saddened because he knows that Maritza is no longer in pain, nor is she suffering anymore. She will always be his second Mom, only now she is also his Guardian Angel.

So let's remember Maritza with the same wisdom that CJ has... for who she was to each and every one of us, of how she gave herself unconditionally, of how she fought for other survivors of the AIDS virus and how, through shared love, she will always live inside of us. I will always love Maritza and carry her inside of me.

Read by Leticia Batista, life-long partner to Maritza, and CJ's second mom, at Maritza's memorial at GMHC.

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research happens in ways that don't hurt them or their communities?

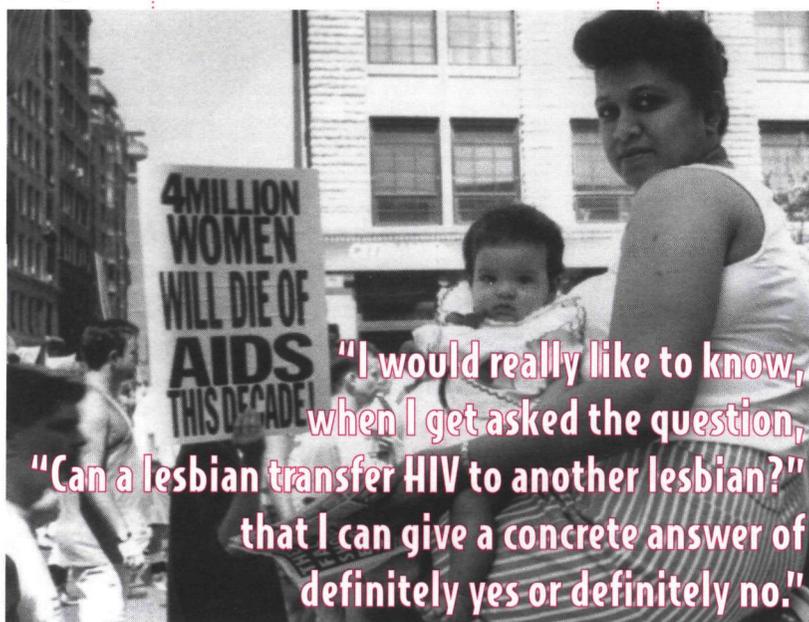
LESBIAN #2: Well, I remember two incidents in particular. This one particular morning, one of the girls hadn't slept all night, she had been out for days and nights, and she finally got some sleep so I needed to do the watch because that was how we stayed safe, watching out for each other when one of us needed sleep. So I did the watch, it was Saturday morning, the research people were looking for her and I told them she was sleeping, then I said, "You know what? Maybe she's going to wake up sick because she's been sleeping for a long time and doesn't have any more drugs."

So I say to her, you know, "do you need money, do you have some drugs for a wake up?" She goes, "No, I have no wake up." So I let the researchers question her. They were questioning her and I was watching from a distance, because I used to also try to keep an eye on everything else. And the main set of questions that morning was about her kids.

About her children?

LESBIAN # 2: About her children. And they even asking her things like, you know, what kind of mother do you think you are? What kind of mother do you think your kids think you are? And things like, "Did you ever hit your children? Did you ever sell your children? Where are your children now? You gave them away?" I mean, aggressive, almost like an accusation. Here is a girl who has been getting high, probably trying to block her feelings, to block out the fact that she has lost her home, has lost her kids, and these people wake her up, fresh and sober and sick, to give her these type of questions. You can forget the money, which was of no use to her that morning, because I had to actually go to the public phone, call the ambulance, because the girl fell down. She

was a mess. She was hysterical crying that she wanted to commit suicide, she had broken her body and she was cutting herself up because she said she was a bad mother. I went with her to the hospital and I was saying, "Man, these people did that but they didn't even give her a phone number for her to call anybody." Or they didn't tell her, you know, "Call us if you need some counseling." They never said to her, "Right now, how do you feel now?" after that questioning. "Do you feel that, you know, we've overwhelmed you, that the questions are hard on you?" Nothing. They just asked the questions and left her there. Now if we didn't have a routine about watching out for each other, she would have com-



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mitted suicide in the lot by herself. LESBIAN # 3: You know, research has been going on for a long time, and people should be aware of certain things being hard on people, even if you aren't a drug user. We had two homeless people in that lot, they were a couple. They weren't drug users, they weren't alcoholics, they were just homeless. I used to see them cuddle up next to each other crying, after the researchers were gone. LESBIAN # 1: They do bring out a lot of feelings because they ask you a lot of personal questions, about, you know, if you had sex with a man, have you sold your body, are you afraid to go home, does your partner hit you, how do you feel

you're taking care of your children? You know, these are personal and it's question after question. They want to know about your first drug experience, everything, they nit pick you.

So what's it feel like to have to answer those questions?

LESBIAN # 1: In the beginning, I didn't feel like I want to share a lot. You know, and then that they know that I'm a lesbian, they asked me a lot of sexual questions, you know, "am I using dental dams or, you know, do I have anal sex. That has nothing to do with, you know ..

How did they find out that you were a lesbian?

LESBIAN # 1: I told them.

But had they ever asked?

LESBIAN # 1: No, they never asked.

LESBIAN # 1: No, they assumed I was straight because I was pregnant. And, you know, I'm not having a problem saying it, so from there on they started to ask me a lot of extra questions. In the beginning they asked me about men, did I ever sell myself, was I ever like

really desperate, and, you know, about if I got high, what kind of things I did. They got pretty personal.

LESBIAN # 1: You can really get depressed.

LESBIAN # 2: Yes, because when you have to think about it, you actually feel it.

Well, wait though. It's important to understand what people go through, it is important for example, to know what happens to a woman that's different than what happens to a man, what happens around what risks we might be taking or what happens around our

kids, what happens in our lives. What could change the way that research gets done so they could ask deeply personal questions if they needed to, yet not treat people badly or leave them out in the cold after their questions were asked?

LESBIAN # 1: I think it depends on the individual, to be honest, because if I was a worker and I was asking these questions, then at the same time I'm watching you, I'm watching how you're answering, I'm watching your expressions, and if I felt that, you know, you're going through changes, I'd be thinking if you needed to take some time out and maybe have some counseling because, I mean, to ask me these really hard questions that you got to dig deep inside to answer and then just kiss them off like, "Okay, here's your money, goodbye," that leaves your brain all screwed up. So I think they need to really observe who are they dealing with. Some people might not have any reaction, say, yes or no, then okay, "Good, I got my money, I'm out of here." But there's people that are really hurt, who have got a lot of unpleasant memories. So they have to be professionally trained to help people they are talking to and know they have to figure out how to stop if someone needs to.

And to do counseling, do referrals.

LESBIAN # 1: Do whatever they need to at that moment. I mean, I'm sure they're getting paid good money to ask people these questions about AIDS and HIV, so they have to be trained to understand the impact of their questions.

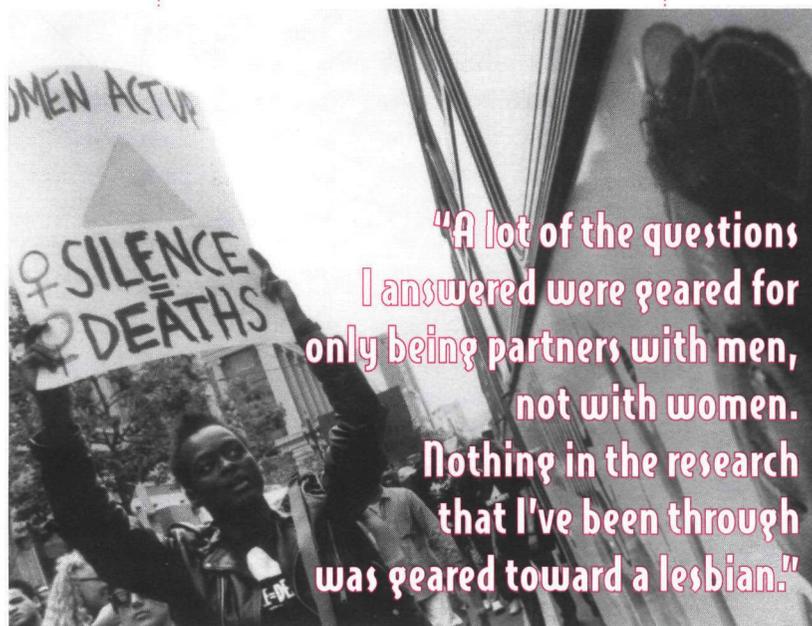
LESBIAN # 1: I want to add this. A lot of the questions I answered were geared for only being partners with men, not with women. Nothing in the research that I've been through was geared toward a lesbian.

That's why we're doing this inter-

view, because they often don't include anything that's particular about being a lesbian or being with women, so you have to be willing to risk their attitude in order to come out and say, "No, actually, I'm with a woman partner, I'm not with a man partner. I might have sex with a man, but I'm with a woman partner, that's who I'm married to."

LESBIAN # 2: Yes, those would be the best ones."

Now, here's the final question: What have you always wanted to say to a researcher about what you wished they understood about the impact of their work on you? If you



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could go to any of the researchers that you ever had to deal with and tell them the truth, about what would have really made a difference for them to understand about the impact of their work on you, what would you say?

LESBIAN # 1: For me, I would say, number one, that it wasn't my fault that I got HIV, it was given to me, and it makes me uncomfortable that all I am is a number to them, and they entice you with a little bit of money. I think they have to see that it's a real person there in front of them, with a real life that matters. Some of us got it without looking for it, and they need to know that. It wasn't only

because you use drugs, I use drugs and I didn't get HIV because I used drugs. I got HIV because I thought I liked somebody and the bastard was infected and didn't tell me. So where does that leave me?

What else do you want to say to them, what else do they need to know?

LESBIAN # 3: They need to know that if you're going to approach people and ask questions in any study, you need to be honest and empathize with the people that you're doing the research with. Not just look at them as, you know, a prostitute, a number, a addict, even if we are, you know. You need to have so much empathy with the lives that they're living. I would like the researchers to understand that they haven't been just where you have been. But if they had been, then maybe they would feel something for us and treat us with respect, you know.

LESBIAN # 2: I think compassion plays a big part in how people relate to people, and researchers have to have compassion for their fellow human being. If they don't, they're cold and they think that everyone else is cold too, you know. Their heart has gone black and

cold, so they assume that your heart is black and cold, and that their questions can't hurt you.

LESBIAN # 1: Also, I think that these researchers should have some kind of contact with either a psychotherapist or psychiatrist, somebody in therapy so that they can teach them how to pick up certain signs, you know.

When certain people are in trouble.

LESBIAN # 1: So when people are in trouble, I think they kinda have to be therapists. You have to be able to pick up certain vibe language, you know. You just can't throw someone a series of questions when they are on the street and then

continued on next page

when you are finished just say, "Go on." It doesn't work that way, it shouldn't work that way. It also has to be somebody that can relax, and can be comfortable with the environment, with the people they research. You know what? If you feel a little skeeved about drug addicts, then don't question drug addicts.

That's right.

LESBIAN # 1: If you feel disgusted with lesbians, then don't question lesbians.

LESBIAN # 1: Right. Just assign researchers to the field that's in their heart!

LESBIAN # 2: The final thing I need to say that is really important to me is that I would really like to know, when I get asked the question, "Can a lesbian transfer HIV to another lesbian?" that I can give a concrete answer of definitely yes or definitely no.

LESBIAN # 1: I just want to be accepted, that's my final statement, as a lesbian. It's hard to talk to somebody that's never been there, that's not affected, that's not infected, and who has no sympathy for people that's gone through all this terrible stuff. How can you trust somebody like that? They don't even know what the joint is, you know. So I think they should train researchers in the communities' experience and then maybe they could, you know, communicate better.

LESBIAN # 3: And if they can't train them, they could always find someone they can partner up with from the community who does understand and can help do it right.

LESBIAN # 1: There needs to be someone that has the experience, the living experience, as part of the research team.

Thank you, you were all wonderful. I think researchers have to be taught to respect and understand the vulnerability of the people who are being asked to participate in the research. But I continue to think that good research is fundamental to understanding what's going on in our communities and our lives.

CHICAGO RESEARCHER RECEIVES FIRST FEDERAL GRANT TO STUDY LESBIANS AND ALCOHOL

Chicago, IL, February 22, 1999. Dr. Tonda Hughes, a nurse researcher at the University of Illinois at Chicago has received a four-year grant from the National Institute of Alcohol Abuse and Alcoholism, National Institutes of Health (NIH), to conduct the first federally funded study on lesbians use of alcohol. This award coincides with the release of a major report on lesbian health by the Institute of Medicine which concludes that additional research is needed to determine if lesbians may be at higher risk for specific health concerns.

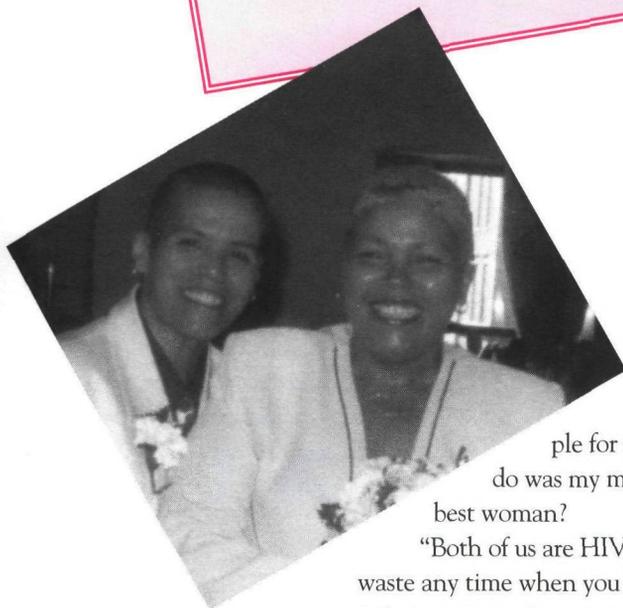
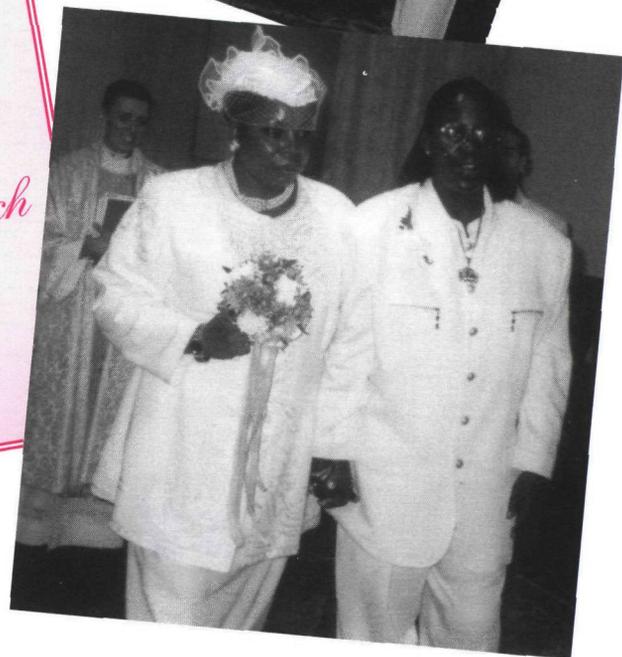
Little information currently exists on lesbians' alcohol use. However, some studies have suggested that, unlike heterosexual women whose use of alcohol declines with age, drinking among lesbians may actually increase with age. Other comparison studies of lesbians and heterosexual women show more alcohol-related problems among lesbians, such as difficulty cutting back on drinking or concerns about the amount they drink. These findings, if supported, have important implications for lesbians health including increased risk of liver and heart disease, accidents and injury, and potential greater risk of breast cancer.

Dr. Hughes, an expert on lesbians and addictions who has studied women's drinking behavior for more than a decade, will explore patterns of drinking and risk factors for heavy drinking among 400 lesbians in the Chicago area, who will be recruited through community groups. Her study is also expected to provide important information on other risk factors including lesbians nontraditional roles, the impact of discrimination and stigma, and social networking behaviors that often encourage socializing in bars.

"This study represents an important breakthrough in lesbian health research, and will provide urgently needed information on a major health concern for lesbians," said Caitlin Ryan, a lesbian health researcher who initiated the National Lesbian Health Care Survey in the early 1980s. Funding by the NIH will help put lesbians and addiction on the federal research agenda.

"Myths and stereotypes of lesbians as alcoholics and heavy drinkers are largely based on studies conducted in the 1970s that recruited most of their samples from gay bars," noted Dr. Hughes. This study is designed to provide a much more realistic picture of the patterns and variability of lesbians drinking, and to provide information for developing alcohol abuse prevention and early intervention strategies.

*Your presence is requested
at the wedding of
Linda Ellis and Toni Jackson
Saturday, the eighth of August
Nineteen ninety-eight
at 10 o'clock in the morning at
Metropolitan Community Church
New York City*



Toni Jackson and Linda Ellis were married on August 8, 1998, at 10:00 A.M. at Metropolitan Community Church (MCC) on West 36 Street. Linda was a peer in the Lesbian AIDS Project and is now a full time staff person in Women and Family Services at GMHC. Linda talked to LAP

Notes about her wedding:

"It was stressful but it was a wonderful wedding. We've been together as a couple for three years. Toni is a wonderful person and I love her a whole lot. Helen Maldonado was my matron of honor, and Iris Maldonado was Toni's best man, or should we say, best woman?"

"Both of us are HIV positive and I think we appreciate each other more. You are really careful not to waste any time when you know both of you is HIV positive. I don't want to waste time on bullshit. I want to enjoy every precious moment."

"She's the first real relationship that I've ever been in that I can actually communicate with my partner. I'm talking about sitting down and just telling my partner exactly how I feel without feeling like I'm saying something wrong, or even if I am, I say what I have to say and I don't worry about the consequences later. Now I'm not scared of me getting beat down or kicked in or, you know, something, because I told the truth."

"Just like any other couple's marriage, you have to take it a step at a time but we're there to help each other, you know. We're going to make it because we know what each other faces. We're going to help each other survive and get home safe. That's our commitment."

FACTS

IN A CALIFORNIA STUDY OF DRUG-USING WOMEN AT RISK FOR HIV, 24% OF WOMEN REPORTED HAVING SEX WITH OTHER WOMEN.

WOMEN NOW ACCOUNT FOR 43% OF ALL HIV INFECTED PEOPLE OVER AGE 15, A RISE OF 2% OVER LAST YEAR.

AN ESTIMATED 9 OUT OF 10 HIV-POSITIVE WOMEN LIVING IN DEVELOPING COUNTRIES DO NOT KNOW THEY ARE INFECTED.

AIDS INCIDENCE AMONG AFRICAN-AMERICAN WOMEN INFECTED THROUGH INJECTION DRUG USE INCREASES AT A RATE OF BETWEEN 10% TO 20% EACH YEAR.

Why All The Hoopla? continued from page 8

Greater effort to do this well, however, will help not just our own communities but other stigmatized communities as well. Perhaps one of the most significant affects the IOM report will have on the research community is to encourage a paradigm shift in what is considered “gold star research.” One of the conclusions drawn by the IOM committee was that “Research on lesbian health, especially the development of more sophisticated methodologies to conduct such research, will help advance scientific knowledge that is also of benefit to other population groups, including rare or hard-to-find population subgroups and women in general.” This is needed because right now there exists a hierarchy of research design which was established during an historical period when research was being conducted primarily on white, heterosexual men - an easy to find and identify population of people. The methods for researching white, straight men will not be feasible for a diverse community of women-who-have-sex-with-women.

The IOM report itself shows how the development of appropriate research models will be developed for the lesbian community—the importance of researcher-community linkages in lesbian health research. The IOM report makes this point very clear, lesbian health research will be done best when diverse members of the lesbian community are included in the design, implementation and interpretation of the study. This will require a tremendous amount of preparation and would be an important project for a foundation to fund: training community based lesbian and bisexual women about research so that they can effectively participate on research advisory boards and on research teams as well as educating researchers about the lesbian and bisexual women’s communities before they even begin thinking about what studies they want to do.

The lesbian and bisexual women’s communities have little experience or training to help us in understanding the worlds of research. For gay and bisexual men the HIV/AIDS epidemic catapulted them into the health and medical science arena, requiring them to know as much, if not more, than their medical providers about the often rapidly changing ideas about managing the disease. It’s not that others aren’t affected by the epidemic, but that particular group of individuals (because of privilege or access) have achieved unparalleled levels of familiarity with health science. If queer men themselves didn’t stay up with the latest research it was always possible that their health provider hadn’t as well and the men knew they could lose valuable months waiting for the information to get to them, if they learned of it at all.

Why is that important? Because if we aren’t involved in the beginning — design through analysis, the likelihood of ignorance about us leading the way is all too real. We have seen what decades of neglect has done to the lesbian community — for twenty years we have known that female-to-female transmission of HIV was possible, yet there is still no credible research to prove our private knowledge and for ten years many lesbians have believed that we are at greater risk of breast cancer, yet again, no proof. We need this information. Funding for health education and services, and for further research, is all directed by what we know. If we can prove that female to female transmission occurs we can get money for health education programs. We also need this information because, quite frankly, our lives depend on it.

1 Badgett, M.V.L., *Income Inflation: The Myth of Affluence Among Gay, Lesbian, and Bisexual Americans*. The Policy Institute-NGLTF, 355 Lexington Ave, 3rd Floor, New York, NY 10017.

2 Chicago researcher
3 Ibid.

Marj Plumb is a health care policy and management consultant living in Oakland, California.

The Institute of Medicine

ly along the multiple dimensions of sexual orientation: sexual identity, sexual behavioral, and attraction or desire. Population-based data on “lesbians” are needed to better understand these dimensions of sexual orientation and the interrelationships among them, the characteristics of the population and how these characteristics interrelate with health status, and the diversity of the population.

Priority 3: Research is needed to identify possible barriers to access to mental and physical health care services for lesbians and ways to increase their access to these services. It is commonly believed in the lesbian community that lesbians do not use traditional health services at the same levels as other women, although population-based data are not available to determine the severity of this problem. Nonetheless, the committee did identify a number of barriers to access to mental and physical health care services for lesbians. These include structural barriers such as the potential impact of managed care and the lack of legal recognition of relationship partners; financial barriers, which may impede access to health insurance coverage; and personal and cultural barriers, including attitudes of health care providers and the lack of cultural competency among providers for addressing the needs of lesbian clients. Developing a better understanding of the health care barriers that lesbians face could help improve access for other underserved groups as well.

AIDS NOW KILLS MORE PEOPLE WORLDWIDE THAN ANY OTHER INFECTION, INCLUDING MALARIA AND TUBERCULOSIS.

RECOMMENDATIONS

The committee makes eight recommendations for improving the knowledge base on lesbian health.

Recommendation 1: Public and private funding to support research on lesbian health needs to be increased in order to enhance knowledge about risks to health and protective factors, to improve methodologies for gathering information about lesbian health, to increase understanding of the diversity of the lesbian population, and to improve lesbians’ access to mental and physical health care services.

Recommendation 2: Methodological research needs to be funded and conducted to improve measurement of the various dimensions of lesbian sexual orientation.

Recommendation 3: Researchers should routinely consider including questions about sexual orientation on data collection forms in relevant studies in the behavioral and biomedical sciences to capture the full range of female experience and to increase knowledge about associations between sexual orientation and health status.

Recommendation 4: Researchers studying lesbian health should consider the full range of racial, ethnic, and socioeconomic diversity among lesbians when designing studies on lesbian health; strive to include members of the lesbians study population in the development and conduct of research; and give special attention to protecting the confidentiality and privacy of the study population.

Recommendation 5: A large-scale probability survey should be funded to determine the range of expression of sexual orientation among all women and the prevalence of various risk and protective factors for health, by sexual orientation.

Recommendation 6: Conferences should be held on an on-going basis to disseminate information about the conduct and results of research on lesbian health, including the protection of human subjects.

Recommendation 7: Federal agencies, including the National Institutes of Health and the Centers for Disease Control and Prevention, foundations, health professional associations, and academic institutions should develop and support mechanisms for broadly disseminating information and knowledge about lesbian health to health care providers, researchers, and the public.

Recommendation 8: The committee encourages development of strategies to train researchers in conducting lesbian health research at both the predoctoral and the postdoctoral levels. (This article is selected excerpts from the Lesbian Health report published by the Institute of Medicine. For a complete copy of the Executive Summary or the complete report contact the National Academy Press at 800-624-6242 or visit the NAP’s online bookstore at www.nap.edu.)

When Numbers Aren't Enough

By Rebecca "Beck" Young for the WSW/IDU Workgroup

For almost 10 years, studies have shown that there is a very serious increased risk for HIV infection among women injectors who have sex with women (WSW) compared to other injectors. Among injectors, only men who have sex with men consistently show higher risky behaviors and higher HIV rates than WSW injectors. Yet many researchers and policy makers, because they are unable to understand this information, continue to overlook or dismiss it.

Let me give two concrete examples of how this important information gets buried. Recently, I submitted an article about HIV/AIDS among women drug injectors who have sex with women (WSWs) to a journal that publishes research on substance abuse/use. One of the reviewers thought the article was interesting and important; the other one insisted that we revise it because they did not believe that WSW injectors could be 2 - 5 times more likely to be infected with HIV than other women drug injectors. We cited 13 studies to show that this was the case, but the person reviewing the article could not make sense of it, so they did not believe it.

The second example concerns the New York City Prevention Planning Group (PPG), the group that decides how to allocate city and state resources for HIV prevention. In 1996, after intensive lobbying by lesbian AIDS activists, I was invited to summarize research on WSW injectors for the PPG Women's and Children's workgroups. I gave a long presentation, based on about 10 different studies of HIV/AIDS among drug injectors, as well as a lot of insights that I collected from lesbian AIDS activists about why WSW injectors require special, custom-made HIV prevention. We had a lively discussion, and I was encouraged by the fact that some of the "movers and shakers" in the PPG seemed to understand the urgency of the situation for WSW injectors. I expected that the next official HIV Prevention Plan would list WSW injectors as one of the special priority populations, and describe the sorts of programs that should get money to prevent HIV among this high-risk population.

I was wrong, wrong, wrong. WSW injectors were nowhere to be found in that report, and not a single dime of prevention money would be earmarked for this group — not in 1997, 1998, or 1999. In spite of all the compelling statistics about increased risk for HIV, I have come to realize that most people simply can't believe these statistics on a gut level — can't believe them enough to act on them — because they don't understand how these numbers can be true.

That should give you a pretty good idea of why a group of researchers (most of whom are also lesbian health activists) at National Development and Research Institutes, Inc. (NDRI) are now conducting a study of HIV risks among women injectors who have sex with women. The study is designed to help all of us — those who know that HIV/AIDS is a serious problem for lesbian

and bisexual women who inject, and those who need to know this but somehow don't — figure out what is going on that puts WSW injectors at even higher risk.

Work on this study began almost four years ago, when a group of researchers and lesbian health activists decided that we needed to study this problem directly if we wanted to understand HIV among WSWs. Before this project, information about WSW injectors came almost entirely from studies that were designed to do something else — for example, look at how neighborhood differences, drug treatment experience, or people's social networks make a difference in the sorts of HIV risks they face. Most of those studies are also different from this project in another important way: they are quantitative, epidemiological studies. That sort of study is great for answering questions like "how many people are doing behavior X or Y?" or even answering who is doing particular combinations of things, or what behaviors typically go together. In other words, those studies are used to generate statistics, which are important.

What those studies can not ever answer is the question "why?" Why do women who have sex with women seem to clean their works less often, buy used works more often, use needle exchanges less regularly, use more of the "riskier" drugs that are usually injected more often, like methamphetamine, and so on? Many of us, of

Why are WSW injectors at high risk?

course, have our theories about why (including me). But we don't actually have much good information beyond our own stories or the stories of other injectors, service providers, or researchers. We don't have information that is systematic, and that was specifically collected in order to ask questions about women injectors who have sex with women.

The main questions behind our research all follow from that "why"? What is it about being a WSW that changes the experience of being a woman who injects drugs, and makes that experience even riskier? Of course, the major reason to ask "why?" is so we can answer the ultimate question behind all of this research: "What do we need to do differently to create effective HIV prevention for WSW injectors?"

These are questions that require a different kind of research than questionnaires or surveys. Instead, the study is based on an ethnographic method, which means that we approach WSW injectors as people with a specific culture, and we are working on documenting that culture. We hang out with women injectors who have sex with women, we try to get as much information as we can about their daily lives, their relationships, their hassles, their coping strategies, their specific ways of shooting drugs or having sex — ANYTHING that might make a difference in the kinds of HIV risks they face, and the ways that they manage those risks. We also collect women's stories, doing a series of five or more long interviews with every woman who agrees to formally participate.

One unique aspect of the study is the partnership between NDRI and the Lesbian AIDS Project at GMHC. Through LAP, we have hired an HIV+ lesbian peer worker, Doralisa Goitia, who does critical referral work, harm reduction counseling and emergency interventions with women we contact in the community. Doralisa brings her long experience as a peer worker with LAP and her intimate knowledge of the circumstances facing many WSW injectors. The peer position demonstrates our commitment to do ethical research—which for us means that we can provide necessary referral and support to the women we meet without sacrificing the integrity of the research. Our partnership with GMHC also involves working closely with Amber Hollibaugh at every stage of the research, which helps keep the research grounded in a perspective informed by years of activism and services to lesbians around issues of HIV.

At this point, we have been doing field research (systematically “hanging out” and observing WSWs) for about 18 months, and we have about another eight months of observation and interviews to go. So far, all of our work has been in New York (specifically in a couple of neighborhoods in Manhattan, because we needed to focus on some limited areas that we could learn very well). Beginning in June, we will conduct some comparative work among WSW injectors

in Boston, to see how things might be different for WSWs in a different city.

We are just now beginning to analyze the data, so it is too early to report results. However, we can report a very general pattern that we found when we first went into the communities where we would interview WSW injectors. We did a series of interviews with service providers, and found that most of them are almost completely oblivious to the existence of WSW injectors. It wasn't that they don't believe “those women” exist; they just don't think there are any women “like that” among their clients. Or if they do, they tended to talk about only the butchest, most gender-bending women that they could think of — nobody seemed especially aware that a dyke is likely to have a girlfriend sitting right there in the waiting room with her. (The number of women we've talked to so far who met their girlfriends in methadone maintenance program waiting rooms is a clue that these service providers are in some kind of parallel universe!) Although we don't know what all the consequences of this sort of ignorance might be, one consequence is clear: these agencies don't know who their clients are, and they dramatically underestimate the proportion of the women they serve who are in relationships with other women. That means that all that integrated service provision that people talk about is not very likely to be happening. What can a program's “family component” look like for a lesbian if the case worker doesn't think she has a family or doesn't know who is in it?

But pointing out that programs overlook the WSWs they serve isn't going to fix the problem, and it would be unfair to imply that those agencies just don't care about lesbians. In fact, quite a few of the service providers we talked to are lesbians, and though they tended to give higher estimates than other service providers for how many of their clients are WSWs, they still tended to identify the same sort of women.

To a certain extent, this is the hardest part of the study, because we know that we have the same problem. Even though most of the staff for this project are lesbians, and everybody is very WSW-friendly, there is no magic decoder ring that allows us to know which of the women we see in a neighborhood is actually a WSW, or which ones are injectors, for that matter. If we wanted to just quickly get 100 WSW injectors and not worry about the fact that all of them would be the most highly visible dykes on the streets, we could finish this project in the next couple of months. But we need to make sure that we are talking to the woman that no one recognizes as a WSW when she's sitting in their waiting room, or standing in the needle exchange line. In some ways, these women are likely to be particularly interesting, because they might be even more isolated and therefore vulnerable.

So we are taking our time, talking to women who don't strike us as very likely to be partnering with women, as well as women who set our “gaydar” sirens off in full force. We spend a lot of time with each woman

who enters the project, and we ask her to introduce us to her friends, her lovers, other women who are like her and other women who are different from her.

Because many of us doing this research are also activists, we tend to see the accomplishments of the research very broadly. So we think that it is an accomplishment that we have raised the awareness of service providers just by going out and asking them about the WSW injectors they serve. We know that this has stimulated some of them to think a little more about how they figure out who is and isn't a WSW or an injector, and we know that telling people why we are doing this research has done a lot to raise awareness of the increased risk that WSW injectors face.

It's also true that before we even collected any data, we had already made history. When we received our funding from the National Institute on Drug Abuse (part of the National Institutes of Health in the U.S. Public Health Service), we became the first large-scale research program focusing on a health issue among lesbian or bisexual women that the U.S. government had ever funded. (There are now several other government-funded studies, as other articles in this issue of LAP Notes describe.)

We look forward to the time when we have results from this study to share, and we urge everyone to keep spreading the word that HIV is an especially serious problem among WSW injectors. We have to figure this out, because too many of our sisters have already paid the ultimate price for our inability to answer “why?”

her risk than other injectors?

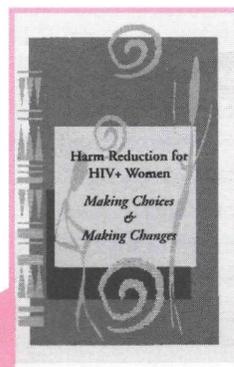
**JOIN LAP AT
LESBIAN & GAY PRIDE
EVENTS IN NYC**

Queens Pride: June 6

Brooklyn Pride: June 12

Manhattan Pride: June 27

Bronx Pride: July 10



**NEW PUBLICATIONS
IN JULY 1999!**

"Making Choices & Making Changes"
A new harm reduction brochure for women living with HIV/AIDS. English and Spanish versions available.

"Invest In Your Child's Future"
For free stickers, call
Child Life Program
212/367-1267



LAP E



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"IN OUR OWN VOICES"

Beginning later this summer, the Lesbian AIDS Project will be devoting four issues of LAP Notes to four people of color communities: *African Diaspora, Latina, Asian Pacific Islander* and *Native American*.

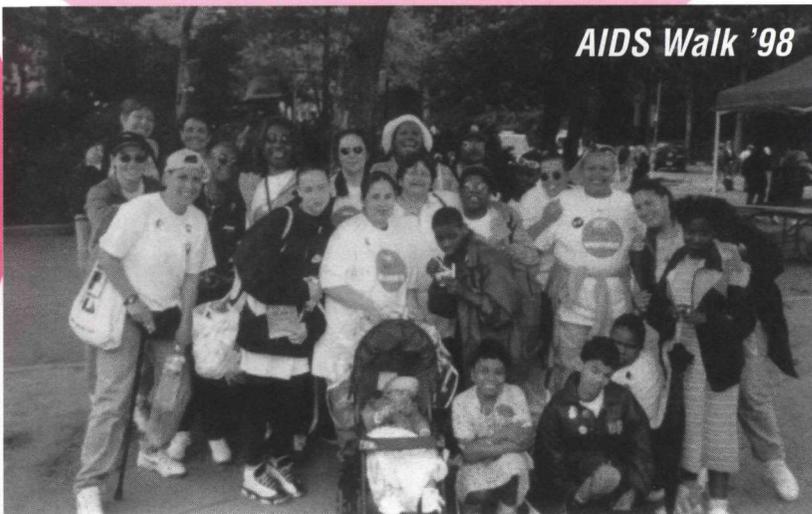
For each issue, members of these communities will be invited to submit articles, poetry, short stories etc. telling of their experiences with HIV/AIDS and/or it's impact on their particular community.

Individuals interested in participating or receiving additional information should contact Tia-Nicole Leak at 212/367-1089.

LAP WOMEN & AIDS FORUM SERIES CELEBRATES LESBIAN PRIDE

Friday, June 4:
"Lesbian Health Issues"
Room 405

Friday, June 18:
"The Lesbian Community
& HIV Transmission"
Room 410



EVENTS

Lesbian Health Research:

by Amber Hollibaugh

This issue of LAP Notes is focused on our need for research and the issues surrounding that research in our communities of women-who-partner-with women for one overwhelming reason; without good research, research which understands the ways in which our sexual identity or sexual behaviors may create unique health needs and research which seeks to bring our diverse communities of women-who-partner-with-women inside the research borders, we will remain vulnerable, continue to be at risk or get sick in ways which are specifically connected to our sexual orientation or our behaviors but which we will have no way to fathom because there is no concrete scientific information to determine what our sexual orientation has to do with our health.

Let me give you an example that is very close to home here at the Lesbian AIDS Project and which is still not resolved, though we have needed this information for many years. LAP has served hundreds of HIV+ lesbians or at risk women-who-have-sex-with-women. But we have no scientific knowledge to share with these women about their ability to transmit the virus sexually to their female (or male) partners when they make love together. We can't tell an HIV+ lesbian what sexual activities might put she and her female partners at the most risk sexually if they are having unprotected sex and we can't point out research which is specific to the particular range of sex acts which they participate in and which can tell them which of those are most or least dangerous to an HIV+ woman or her female lover — or even if they are actually dangerous at all! — because there's no lesbian specific scientific research yet to help us determine sexual transmission of HIV betwe women partners. So. We just don't know.

LAP has been in existence since 1992. By 1995 we had finally gotten the CDC to hold its first meeting with lesbian health activists in order to discuss this particular issue and the crisis it reflected for those of us who were positive or working with lesbians with AIDS. Three years after that meeting, the first small grant was finally given to a Yale research team to try and determine if female to female sexual transmission was possible, but it will be another two years, if we're lucky, before we have any kind of results or even a scientific glimmer of a response will be available. That's six and a half years since we officially began to demand an answer and sixteen or more years into the epidemic itself — with no knowledge to go on. That's where the mistaken idea that “lesbians don't get AIDS” has left us and where LAP finds itself when working with its lesbian clients and friends who are at risk or living with HIV. No woman's sexual and HIV risks should be determined by what I think, or the woman sitting next to me, or her sister or some well meaning doctor either. LAP and the women it represents across this country and globally, need clear cut,

scientific explanations. We need research, the right kind of research, to help us begin to find some answers to these questions and to many others. And, we need to help set the terms of that research so that it actually respects and understands the women it's studying and we can have faith in the importance of our participation in the research and the results of the work being done.

This is going to take work on our parts in more ways than we are used to. We will need to do more than the political work of mobilizing and advocating for better research which includes lesbians. We need to train ourselves and our communities to understand the complex world of research — how it operates, what makes it tick, how it is done and what is necessary to fundamentally determine a result. We need to demand of ourselves that our own communities understand the needs and requirements of that research. Conversely, we must insist that researchers working in our communities actually listen to the complicated layers of information we possess internally about how our communities function and how that may affect our health.

No woman's sexual and HIV risks should be determined by what I think, or the woman sitting next to me, or her sister, or some well-meaning doctor, either.

LAP and the women it represents across this country and globally, need clear cut, scientific explanations.

Does It Really Matter?

And any research in which we play a role must recognize our many differences — of race or class or age or sexual practices, of the ways that “lesbian” or “women-who-have-sex-with-women” is nuanced, differentiated, changed by time or history or religion or context. Just as we need to educate ourselves to understand how research is done in order to participate in that research, we need to insist that credible, serious, demanding research about our lives — as women, as lesbians, as people of color, as young women, as mothers, as working class or upper-middle class folks, as women in prison, as the total people that we are — whatever that might be, clearly be reflected in the research which will help define and unravel the secrets of our health, both its similarities and its differences.

We need this knowledge desperately. It will mean that we must step up to the challenge it presents us with as well as understand the opportunities it represents for our future and the futures of the women who follow us. After all is said and done, our bodies, our health and wellness are intrinsic to our existence and our survival. We need to become full partners in whatever the health research focusing on lesbians can tell us about our health and our lives. We need to educate our communities to participate as educated consumers, we need to openly be a part of the scientific teams who do that research and to be part of the folks who determine the meanings of those results. Good healthcare is about staying alive, preventing illness or minimizing its affects, understanding what puts us at risk and how to reduce or eliminate that risk. This coming period will begin to create research which is for our bodies, our lives, our lovers, our children, our communities, ourselves. It will mean we are counted in this time. It will mean that in the larger, difficult world we all traverse, our lives matter.

Women's Rights & Responsibilities

An important part of taking charge of one's health is remembering that, should you choose to exercise them, you have certain rights as a consumer.

1. I have a right to be treated as an equal human being.
2. I have a right to be listened to and have my problems taken seriously.
3. I have a right to an explanation that I can understand in my native language on any questions concerning my healthcare.
4. I have a right to know the choice I face in getting tested for any health problem, and to have the possible side effects of any drugs or surgical treatments clearly explained.
5. I have a right to choose the types of treatment I prefer from among the options offered to me by my doctor.
6. I have a right for normal events in my life, such as pregnancy and menopause, not to be treated as diseases requiring treatment.
7. I have a right to choose natural therapies and not to be ridiculed for doing so.
8. I have a right to request a second opinion on any major surgery or health decision.
9. I have a right to refuse any drug or surgical treatment.

It is equally important to exercise your responsibilities to yourself.

1. I have a responsibility to become knowledgeable about my body and how it works.
2. I have a responsibility to learn as much as possible about my health problems so I can make informed choices.
3. I have a responsibility to exercise, look after my diet, reduce stress and relax on a regular basis.
4. I have a responsibility to avoid pressuring my doctor into giving me drugs when I don't need them.
5. I have a responsibility to prepare my questions for my doctor beforehand and to schedule adequate appointment time to discuss them.
6. I'm ultimately responsible for my healthcare, using my doctor as a resource rather than an authority.

from Women Alive (Take Charge of Your Body: A Woman's Guide to Health)

HIV+ WOMEN NEEDED FOR STUDY

The Yale Woman to Woman Sexual Transmission Study is looking for women who are HIV+ and wish to be involved with this project. If you want more information about the study, or to find out if you are eligible, here are numbers for some of the study sites now up and running and a general number if these are not in your area or the sites don't yet have phone

numbers to call. If you are eligible, you can participate regardless of what part of the United States you live in.

In New York, call Ibis Castro at The Positive Women's Project at Montefiore Medical Center, 718/920-7294.

In Washington, DC, call Ellen Kahn, Director of Lesbian Services at Whitman-Walker Clinic, 202/939-7877.

In San Francisco, the phone num-

bers are not finalized, but look for announcements in local clinics and community-based organizations in the near future.

If these numbers are not in your area or not yet finalized and you want more information, you can call collect to the director of this study, 203/737-1976, and ask to speak to Kathleen Ethier.

AFRICAN-AMERICAN AND HISPANIC WOMEN TOGETHER REPRESENT LESS THAN ONE-FOURTH OF ALL U.S. WOMEN, BUT ACCOUNT FOR MORE THAN THREE-FOURTHS (76%) OF AIDS CASES AMONG WOMEN IN THIS COUNTRY.

1999 National Conference on Women and HIV/AIDS

October 9-12, 1999
Los Angeles Convention Center
Los Angeles, California

A Forum for Collaboration
HIV
1999

THE 1999 NATIONAL
CONFERENCE ON
WOMEN AND HIV/AIDS

To Request an Abstract Form or More Information Contact

Women's Conference
Meeting Department
19 Mantua Road
Mt. Royal, NJ 08061
Phone: 609/423-7222, x350
Fax: 609/423-3420

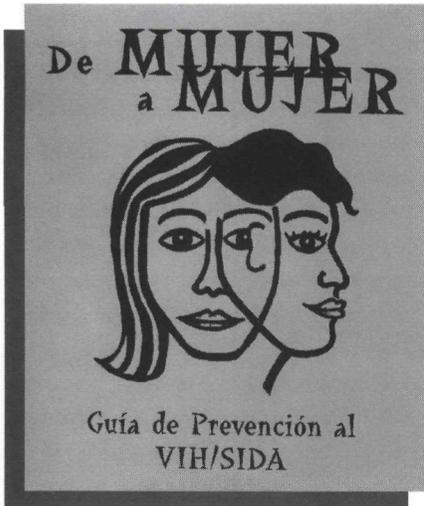
For Information Regarding Exhibits/Sponsorship Contact

Women's Conference Exhibits
19 Mantua Road
Mt. Royal, NJ 08061
Phone: 609/423-7222, x262
Fax: 609/423-3420

The LAP Boutique

Publications and Products for Women

De Mujer a Mujer



75¢ each
(50 or more: 50¢ each)

Spanish language safer sex brochure. Helpful illustrations with easy tips. Great sexy reading material!

All of these materials are FREE to Women Living with HIV

Pussy Pack



\$2.00 each
(100 or more: \$1.50 each)

Pocket size, easy to travel with and fun to share!

Contains one individually-wrapped dental dam, one condom, one packet of lube, enclosed in a colorful information packet

How can you get to The LAP Boutique?

Call 212/367-1355 or write to LAP, 119 West 24 Street, New York, NY 10011

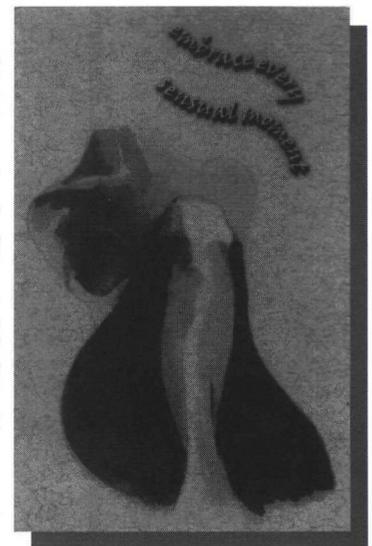
Safer Sex Handbook for Lesbians



\$ 1.00 each
(50 or more: 75¢ each)

A sexy read for one or more and great to look at! Photo illustrated safer sex information for lesbians.

Women's Safer Sex Kit



\$2.50 each
(100 or more: \$2.00 each)

Deluxe model for safer play! Enough to share!

Contains two finger cots, one latex glove, one individually-wrapped dental dam, one packet of lube, and resource palm card enclosed in detailed information packet

Lesbian Health Network E-Mail List

FREQUENTLY ASKED QUESTIONS

Connie Winkle
LHINetwork List Moderator

WHAT IS THE PURPOSE OF THE LIST?

The purpose of the Lesbian Health Information Network E-mail List is to create a worldwide network for distributing information relating to lesbian health research, education, and services, and to serve as a resource and networking tool for those involved in lesbian health.

HOW DO I SUBSCRIBE?

To subscribe, send a request to LHINetwork@aol.com with:

- your full name
- e-mail address
- how you heard about the list (through an organization, individual, web site, etc.).
- a brief description of your work in lesbian health (i.e., organization or university affiliation, research, etc.).

WHO ARE MEMBERS?

The Lesbian Healthy Information Network E-mail list consists of 200+ persons involved in lesbian health from around the world.

WHO MAINTAINS & MODERATES THE LIST?

Connie Winkle, M.S.W., of Arlington, Texas - consultant, researcher and women's health advocate. My business is Winkle Consulting & Research, through which I provide services to nonprofit, government, and other organizations, including grant writing, program development, research, and technical assistance. I am co-creator of a new not-for-profit health organization called the Health Resource Network of Texas.

WHAT INFORMATION WILL I GET IN MY E-MAILBOX?

You will receive announcements and information concerning: - lesbian health education and services

- lesbian health research and journal articles
- information about lesbian health organizations and projects
- queries from other list members needing assistance with lesbian health resources

CAN I POST A MESSAGE TO THE LIST?

Sure. Send your message exactly as you want it to go out with a request to post it to the list to LHINetwork@aol.com and it will be posted. List members are encouraged to send information they would like publicized about their research, journal articles, organizations, services provided, queries about lesbian health issues, education, outreach, etc. to LHINetwork@aol.com for posting. (The moderator reserves the right to decline to post messages deemed inappropriate for the list. Messages to be posted must relate to lesbian health or mental health.)

IS THERE A WEB SITE?

Not yet, but I am hoping to create one in the coming year.

HELP! MY E-MAIL ADDRESS IS CHANGING... WHAT DO I DO?

Send your request to change your subscription address to LHINetwork@aol.com. Please include your name, old address, new address and date you want the change to go into effect.

HOW DO I UNSUBSCRIBE?

Send a message with your request to be removed to LHINetwork@aol.com.

I'VE GOT MORE QUESTIONS...

Send an e-mail to LHINetwork@aol.com and I'll do my best to answer your questions or research the answer for you.

THE LHINetworking PROJECT

The LHINetworking Project is a compilation of information about LHINetworking list members who would like to share information about their work in lesbian health with others for networking purposes. Participating list members complete a biography form and send in to be compiled with others to be sent to participating members on a quarterly basis.

Here are the basic rules:

1) To participate in the LHINetworking Project, please copy the form onto a new e-mail, fill in the areas you feel comfortable with, and e-mail to LHINetwork@aol.com. Please note: You do not have to complete all of the information in order to participate. Simply delete any categories you do not wish to answer. When completing the form, please do not type in upper case letters as your information will be easier to read if you do not.

2) Participating in this project is open to list members of the Lesbian Health Information Network. However, it is entirely optional for list members to participate. You do not have to participate to remain on the LHINetwork list.

3) Only those who participate will automatically receive a copy of the LHINetworking Project list. If for some reason you do not feel comfortable participating, but feel you would benefit by being able to network with those who are on the bio list, send an e-mail to me at LHINetwork@aol.com with a request for a copy of the list and an explanation of why you are not participating. It will be at my discretion as the list owner as to whether or not I will honor the request.

4) The LHINetworking list will be compiled into one text file which will be alphabetized by participants' last names.

Resources

Lesbian Sensitive HIV/AIDS Services in the Tri-State Area

This is not a complete listing. To be added to this list contact LAP.

▲ Connecticut

Hartford Gay and Lesbian Health Collective
PO Box 2094
Hartford, CT 06145-2094
Linda Estabrook 860/278-4163

▲ New Jersey

New Jersey Women and AIDS Network (NJWAN)
5 Elm Row, #112
New Brunswick, NJ 08901
Plyshette Bethea 732/846-4462

▲ New York

ACLU Lesbian & Gay Rights AIDS Project
125 Broad St. 18th Fl.
New York, NY 10004-2404
Matt Coles 212/944-9800 x544

APICHA

Asian & Pacific Islander Coalition on HIV/AIDS Inc.
Queens Community Center
74-09 37 Avenue, Suite 400
Jackson Heights, NY 11372
718/457-9662

Audre Lorde Project
Center for Lesbian, Gay, Bisexual, Two Spirit and Transgender People of Color
85 South Oxford Street
Brooklyn, NY 11217
718/596-0342

Body Positive/PWA Coalition
19 Fulton Street, Suite 308B
New York, NY 10038
212/566-7333
Hotline: 800/566-6599

Bronx AIDS Services
1 Fordham Plaza, Suite 903
Bronx, NY 10458
Yvonne Arroyo 718/295-5605

Callen-Lorde Community Health Project
208 West 13 St.
New York, NY 10011
Valerie Walker 212/675-3559

GMHC Child Life Program
119 West 24 Street, Floor 2
New York, NY 10011
212/367-1267

God's Love We Deliver
166 Avenue of the Americas
New York, NY 10013
Juanita Harvey 212/294-8120

HIV Uninsured Care Programs
PO Box 2052
Empire Station
Albany, NY 12220-2052
800/542-2437

Hetrick Martin Institute
2 Astor Place, third floor
New York, NY 10003
212/674-2400

IRIS House Women & AIDS Women's Center
2271 Second Ave.
New York, NY 10035
Iris Maldonado 212/860-3700

Lesbian AIDS Project, GMHC
119 West 24 St., fourth floor
NY, NY 10011
212/367-1355

Montefiore Medical Center Adolescent AIDS Program
Miriam Ramos 718/882-0023

New York Bisexual Network
208 West 13 St.
New York, NY
212/459-4784

PONY (Prostitutes Organization of New York)
271 Madison Ave., Suite 908
New York, NY 10016
212/713-5678

Project Connect Lesbian & Gay Center
208 West 13 St.
New York, NY 10011
212/620-7310

Shades of Lavender
502 Bergen St.
Brooklyn, NY 11217
Karen Lippitt
718/622-2910 x103

Southern Tier AIDS Program
122 Baldwin St.
Johnson City, NY 13790
607/798-1706

Women In Crisis
212/665-2018

Services for Lesbian Inmates & Ex-Offenders who are HIV-Positive

A.C.E. OUT
AIDS Counseling and Education
8 West 38 St. Suite 804
New York, NY 10018
Lanere Rollins 212/398-4041

ACLU - National Prison Project
1875 Connecticut Ave., NW #410
Washington, D.C. 20009
202/234-4830

AIDS In Prison Project
135 E. 15 St.
New York, NY 10003
Steve Nesselroth 212/673-6633

The Alliance for Inmates with AIDS
Romeo Sanchez 212/675-3288

El Rio/Alternative Recovery Program
809 Westchester Ave.
Bronx, NY 10455
718/842-0500

Fortune Society HIV-Ethics Project
39 West 19 St., seventh floor
New York, NY 10011
212/206-7070

HIV/AIDS Hotline for Prisoners
212/674-0800 Tu & Th 3-8 pm
Collect calls accepted

Prison Pen Pal Project
Body Positive/PWA Coalition
19 Fulton Street, Suite 308B
New York, NY 10038
Althea Brooks 212/566-7333

Women's Prison Association
110 Second Ave.
New York, NY 10003
Yvonne Soto 212/674-1163 x58

Women's HIV/AIDS Newsletters

WISE Words
Project Inform
205-13 St. #2001
San Francisco, CA 94103
800/822-7422

Women Alive (Eccos Fememinos)
1566 Burnside Ave.
Los Angeles, CA 90019
213/965-1564

WORLD
414-13 St. Second Floor
Oakland, CA 94612
510/986-0340

Pediatric HIV/AIDS Resources

Just Kids (caregiver support)
POBox 42, New York, NY
800/341-1880

National Pediatric and Family HIV Resource Center
30 Bergen St., ADMC-4
Newark, NJ 07107
800/362-0071

It will be sent out to participating list members on a quarterly basis. It will be sent as via e-mail with the list as an attached file. An entire list update will be conducted annually, as list members interests, employment, etc. may change over time.

That covers all the housekeeping. If you have questions, please e-mail me at LHINetwork@aol.com.

Thanks in advance to all of you who will be participating in this project. This is an effort to bring together those of us who are working on lesbian health all over the world to share ideas, information, and research.

LAP Notes is a GMHC publication which is free to all HIV positive lesbians and women who sleep with women (WSW), to women who are in prison or have been incarcerated, women who have been institutionalized in drug rehab, halfway houses and juvenile detention, women who can't afford a subscription and lesbians who are at-risk for HIV/AIDS. Institutions, libraries, organizations and individuals who can afford a subscription are asked to help LAP by sustaining us through a subscription. Please write to:

Lesbian AIDS Project (LAP)
The Tisch Building, 119 West 24 St. Fourth Floor
New York, NY 10011-1913
212/367-1355

Publication of the name or photograph of any person or organization appearing or listed in *LAP Notes* may not be taken as an indication of the sexual orientation or HIV status of that individual or group, unless specifically stated. The contents do not necessarily represent the opinion of the Lesbian AIDS Project, unless specifically stated. *LAP Notes* welcomes letters, queries and unsolicited articles. All submissions may be edited.



GMHC

LAP
The Tisch Building
119 West 24 Street
New York, NY 10011-1913