PITT MEN'S STUDY
NEWS AND NOTES

Spring 1989
(412) 624-2008

THE CAB SUMMIT

Pittsburgh had the pleasure of hosting a meeting of representatives from the Community Advisory Boards of the other MACS sites. Judith Johns, Executive Director and Sean Rearden, Board Member of Howard Brown Memorial Clinic represented Chicago, Niles Merton, publisher of the Advocate represented L.A. and Lewis Hughes and Curt Decker represented Baltimore.

The meeting with the Pitt Men’s Study Community Advisory Board led to a number of recommendations about increasing public health education for our cohort and the community in general and about activities which can help maintain participation of our volunteers. These recommendations will be discussed with all of MACS’ principal investigators.

2. Reviewed all Study protocols, ads and recruitment materials. (1984-present)
4. Organized and staffed a phone bank to recruit men into our study. (1985)
5. Distributed 40,000 condoms and 15,000 safe sex brochures during our recruitment drive. (1984-present)
6. Helped organize workshops and conferences for volunteers. (1985-present)
7. Reviewed the protocols for the HIV Result Disclosure, AIDS Prevention Project, AIDS Information Mobilization, the Pitt Treatment and
Evaluation Unit and the Pennsylvania/New York AIDS Regional Training and Education Center. (1985-present)

8. Organized and implemented a minority outreach program consisting of ads, workshops, flyers and a person to person campaign. (1986-present)

9. Developed, approved and revised PMS's safe sex message. (1985-present)

10. Worked for increased funding for AIDS education and services. (1986-present)

11. Obtained a City Council resolution recognizing the work of our volunteers. (1988)

12. Worked to have "sexual orientation" added to the University's non-discrimination policy. (1988)

13. Worked to have HIV issues integrated into the curricula of the health science schools and the School of Social Work. (1988-present)

14. Worked to have the University donate $25,000 to local AIDS service groups. (1988)

15. Organized a memorial service for study volunteers and others who have died of AIDS. (1988)

MEET OUR STAFF

Monto Ho, M.D., Coinvestigator

Dr. Ho came to Pittsburgh via Hunan, China and Boston, Massachusetts. After graduating from Harvard University and Harvard Medical School with honors including magna cum laude and phi beta kappa, he worked at Harvard with Dr. J. Enders, a renowned virologist. In 1959, he was appointed to the faculty of the Graduate School of Public Health and the Medical School at the University of Pittsburgh.

His research and clinical work in virology and infectious diseases led to many honors and awards including the Fulbright and Josiah Macy fellowships, election to the Association of American Physicians, Academia Sinica (Chinese Academy of Science) and Delta Omega Honorary Society.

In addition to his work with the Pitt Men's Study, Dr. Ho heads the Department of Infectious Diseases and Microbiology where most of the AIDS research in Pittsburgh is based. He is the Principal Investigator of the Pitt Treatment and Evaluation Unit, which performs clinical trials on the effectiveness of drugs against HIV infection, as well as of the Pennsylvania/New York AIDS Regional Education and Training Center. His 200 published articles on infectious diseases and microbiology bear witness to his drive and intellect. His patients can attest to his compassion and concern.

Amy Enrico, Retrovirus Laboratory Supervisor

Amy was born and raised in Jeannette, Pennsylvania. She came to the University of Pittsburgh for her Bachelor of Science degree in neurobiology. While working as a laboratory assistant in Greensburg, she heard about and became interested in AIDS. When an opening developed at the Pitt Men's Study, she applied and was hired. Promoted to supervisor of our Pittsburgh Retrovirus Laboratory, a specialized lab dealing with biohazardous material, she oversees many of the study's most critical experiments dealing with HIV. Covered head to toe in a protective suit, Amy works in a negatively pressurized lab. The Retrovirus lab is specifically used to grow virus from blood samples and test the reactions of anti-viral drugs on them.

She is comfortable with the precautions instituted at the lab. However, when her friends first heard of her job, she would be teased by people who expressed fear of using her drinking glass. "At first, they made a lot of jokes but after a while I got the impression that they meant them," she says.

Living in Shadyside now, she feels that attitudes of people are changing. "People now seem more caring and less homophobic. Ultimately, I think they realize that sexual orientation is not the issue, illness is." She added, "Meeting people with AIDS has given the disease a human
face for me and motivated me to work even harder to try to understand this disease."

When not riding her bicycle (she logs 200 miles a week), Amy is studying for a Masters Degree in Civil Engineering.

PITT MEN'S STUDY GOES TO MONTREAL

Pitt Men’s Study researchers and their associates in MACS have proposed over forty papers for presentation at the Fifth International AIDS Conference in Montreal in June, 1989. These papers deal with a wide-range of issues including early detection of HIV infection, co-factors leading to the development of AIDS and cellular immune response to infection.

Copies of the abstracts accepted for the conference will be available in the clinic along with copies of articles published based on our data.

"WHAT ONE SHOULD KNOW ABOUT CLINICAL TRAILS"

by Monto Ho, M.D.

Through clinical trials, researchers evaluate new methods of treating and preventing HIV infection and AIDS. These methods are developed in the laboratory but they must ultimately be evaluated in the patient.

The word "trial" in clinical trials means that we are testing an unproven modality of treatment and asking a question that can only be answered in humans. A clinical trial is an experiment. By definition, outcomes of experiments are unknown. Experiments can succeed or fail, and failure is part of the risk of any experiment.

HIV infection and AIDS are still incurable and since results from laboratory research are pouring out at an exponential rate, and many need to be evaluated clinically, clinical trials have become very important and will continue to increase in importance.

Should a Person be Interested in a Clinical Trial?

We encourage eligible individuals to consider taking part in clinical trials. By doing so, they join in the relentless war against AIDS. They may also benefit from the experiment. They may feel better or live longer. But that benefit cannot be guaranteed, because if it could, the trial would no longer be an experiment. The participant may gain nothing except excellent free care and follow-up. However, he or she will not be denied any medical care that is indicated by the state of the art.

A trial is different from a medical prescription. A choice is involved. The patient must give "informed consent" in order to participate in a trial. When we hear in the lay press or media that people are complaining because not enough patients have been enrolled in clinical trials for AIDS, this suggests a potential misunderstanding of what a clinical trial is meant to accomplish. Not getting into a clinical trial is clearly not the same as being denied treatment. That is because clinical trials are not accepted modalities of treatment but are experiments. The number of subjects who should be enrolled in a trial is generally dependent on how many volunteers are needed to conduct the experiment properly and not on how many patients are available or in need of treatment. However, in desperate medical situations such as AIDS and cancer, it is sometimes difficult for the general public to understand this distinction and we are often psychologically impelled to take an activist position. Doing something, even of unproven value, seems at times to be better than nothing. Some people think that clinical trials are the way by which "something" is done. We agree with this view as long as clinical trials are not expected to take the place of all therapy. What we do not agree with is to equate the use of any untried therapy with a "clinical trial". In a sense such usage is an experiment, but it may not be a scientific one. We must recognize the fact that uncontrolled, unwarranted and unscientific clinical trials are wasteful, misleading and cruel. They evoke hope that may be unfounded.
UPDATE ON STUDY PUBLICATIONS

The following papers have been or will be published in medical and scientific journals. They have been prepared based on the data we have collected in the Pitt Men's Study and, in some cases, the other MACS sites. They represent the continued generosity of our volunteers without whom this research could not have been done:


11. Saah AJ, Farzadegan H, Fox R,


AIDS UPDATE
1989 CONFERENCE

On May 15, 1989, a major conference for primary health care providers will be offered by the Department of Infectious Diseases and Microbiology. This conference will present state of the art knowledge on a number of issues relevant to physicians, nurses, dentists, social workers, pharmacists, allied health professionals and therapists. The following is a schedule for the day:

AIDS UPDATE
May 15, 1989
Holiday Inn, Oakland

9:30am Pathogenesis of HIV infection and Vaccine Development
Dr. Robert Schooley, Harvard Medical School

10:15am Discussion

10:30am Break

10:45am HIV Infection and Intravenous Drug Use
Dr. Mark Smith, Philadelphia Commission on AIDS

11:30am Discussion

Noon Lunch

1:00pm Prevention of HIV Infection
Dr. Michael Spence, Hahnemann University

1:45pm Discussion

2:00pm Recent Developments in the Treatment of HIV Infection/AIDS
Dr. Monto Ho, University of Pittsburgh

2:45pm Break

3:00pm Panel Discussion: The Problems of Integrated Health Care for Persons with HIV/AIDS
Moderator: Dr. Monto Ho
Panelists:
Dr. Bruce Dixon
Dr. Susan Hunt
Ms. Cindie Klemanski
Dr. Nancy Obus

4:30pm Evaluation

5:00pm Adjournment

Interested people who wish to register should call 624-1895.
Raw eggs that were contaminated with Salmonella enteritidis bacteria have caused some recent outbreaks of foodborne illness. Scientists strongly suspect that Salmonella bacteria can be transmitted from infected laying hens directly into the interior of the eggs before the shells are formed. The full extent of the problem is not yet known, but scientists are working to find solutions.

There is a risk of contracting salmonellosis from raw or undercooked eggs. Eggs are a perishable product and should be treated as such. As with any other perishable food product, proper storage and cooking of eggs is necessary to prevent the growth of potentially harmful bacteria. Consumers should continue to follow safe food-handling practices when preparing eggs.

Special precautions are needed, however, when eggs are served to or eaten by people in high-risk categories who are particularly vulnerable to Salmonella enteritidis infections: the very young, the elderly, pregnant women (because of risk to the fetus), and people already weakened by serious illness or whose immune systems are weakened.

PMS CONFIDENTIALITY

Volunteers are reminded that confidentiality of records remains a high priority for the staff of the Pitt Men's Study. The following describes some of the ways we use to insure it:

** The study has received a "Confidentiality Certificate", "DA-84-10", from the federal government. This means that no individuals, court, or governmental agency can force us to turn over information which identifies our volunteers.

** Each volunteer receives a numerical code. That number is the only identifying information placed on questionnaires and specimen containers.

** Identifying information is collected so that we can send volunteers their test results and questionnaires. That information, along with the volunteers' numbers, is triple-locked in a secure place. Identifying information is not sent to the National Institutes of Health. Volunteers' identities will not be revealed in any description or publication of research.

** Only Pitt Men's Study staff have access to that information and will use it only to contact the volunteer.

** Our staff is required to communicate with volunteers only in the ways the volunteer chooses.

** If the volunteer chooses to have us contact him by phone, we always use discretion. We cannot and do not discuss the study or test results with anyone but the volunteer.

** The envelopes we use for mailing test results are security envelopes. The inside of the envelope is shaded so that no one can see the contents unless they open the envelope.

** Our return address on the envelope is a Post Office Box number. Our name does not appear.

** All study staff have signed a legal agreement with the University pledging to maintain strict confidentiality. If any staff member violates this agreement, they can be fired and sued.

Remember, if you sign a consent form and have us send your records to your physician, any records in his or her files are only protected by standard medical confidentiality safeguards. For example, while records in our possession are protected from subpoena, records that you have us send to your doctor can be subpoenaed from your doctor. Before you consent to have your records sent anywhere from our study, please consider confidentiality issues.
MISSED APPOINTMENTS?

The great majority of our volunteers have consistently attended all of their appointments at our clinic. However, some men have missed one or more appointments. These men should know that no matter how long since their last visit, they are still needed. For research to be scientifically valid, it is essential that the numbers of volunteers remain constant throughout the time of the study.

So, if you have not been in for a while, please come in again. By doing so you will learn new information about your health and about AIDS and you will enable us to successfully include up-to-date information from you in our study.

If you have missed appointments, or have not been in during the last six months, please call (412)624-2008 to schedule.

LUTHERANS CONCERNED/ PITTSBURGH

A local chapter of Lutherans Concerned has formed in Pittsburgh. The charter members hope to create a place where all people feel welcome; lesbians, gay men and straight alike.

The membership of Lutherans Concerned is strictly confidential. As well as providing fellowship, another main goal of Lutherans Concerned is to dialogue with the Lutheran Church.

Lutherans Concerned/North American, which has been in existence since 1974, has more than thirty chapters throughout the continent. It has published a number of educational documents about homosexuality and also provides a speakers bureau for congregational and organizational use.

For information regarding upcoming activities, contact Reverend Ruth Becker at the Lutheran University Center, phone 682-6836.

WEDGE COMES TO PITTSBURGH HIGH SCHOOLS

The Wedge Project which has been very successful in such cities as San Francisco and Atlanta is coming to Pittsburgh. A consortium of educators and AIDS service agencies is looking for a few good volunteers to participate in this unique program. The goal of the Wedge Project is to stop the spread of HIV infection among adolescents. Through four presentations which include basic facts about HIV and risks, discussions, exercises, and personal histories led by a team of trained speakers, the student begins to recognize his or her own level of risk for HIV infection.

To accomplish this process of self-discovery, health care professionals, educators and especially persons with AIDS or ARC will volunteer to speak to the tenth grade students in Allegheny County. In order to be qualified for this important community service, a volunteer must complete a training seminar and commit to two sessions per month after the training. If you would be interested in participating, contact Tammy at 363-6500 for more information and dates.

MOVED OR CHANGED YOUR PHONE NUMBER?

If you have moved or changed your phone number since your last visit, please let us know by calling (412) 624-2008.

CALL FOR JUNE 30 AS A NATIONAL DAY OF MOURNING

The National Gay & Lesbian Task Force Privacy Project and CRY OUT! (Pittsburgh’s Lesbian/Gay action group) are calling for a project to commemorate June 30, 1989, the third anniversary of the Hardwick decision. In Bowers vs. Hardwick, the US Supreme Court ruled 5-4 that Gay men and Lesbians have no constitutional right to engage in private, adult, consensual sexual behavior, and upheld the rights of states to criminalize Lesbian & Gay sexuality. Activities including letter writing campaigns, letters-to-the-editor blitzes, demonstrations at the US Supreme Court Building, educational forums, and demonstrations at the state capitol are being planned.

AIDS TRAIN THE TRAINER PROGRAM SLATED FOR PITTSBURGH

The University of Pittsburgh has announced an AIDS Train the Trainer

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Program designed for primary care health professionals (physicians, dentists, nurses, social workers, and administrators) who are interested in becoming HIV/AIDS trainers within their own agencies or facilities. Participants will attend a symposium on May 15th and attend an additional program on May 16th. Applications will be reviewed by the Pennsylvania/New York AIDS Regional Education and Training Center. Those admitted will be awarded a tuition scholarship. Those applicants accepted in the program must agree to train at least 25 health professionals upon completion of the program. Training is supported by a grant from the Health Resource and Services Administration Bureau of Health Professions of the Department of Health and Human Services (#HRT 000047-01-1) and by the Howard Heinz Foundation. Registration for this program is limited.

Education of trainers on May 16th will be provided through the use of discipline specific individualized learning and experience. For further information you or your staff should contact the Pennsylvania/New York AIDS Regional Education and Training Center office at the University of Pittsburgh, Graduate School of Public Health, Room 207F Parran Hall, Pittsburgh, PA 15261. The phone number is 412-624-1895.

OUT AND ABOUT

Joseph Carra, M.S. has recently joined our staff as the Neuropsychiatric Substudy Coordinator.

The study staff said a sad farewell to Dean Harbury, the Neuropsychology Substudy Data Manager. Cindy Sutton was hired to take over his duties.

Carol Licata joined our clinic staff. She will be profiled in our next newsletter.

PMS staff members Ric Witt, Ryan Dappen, David McAdoo, Tony Silvestre and co-investigator Dr. Monto Ho were seen at the 1989 Lambda Ball.

LIFE-LINK MEDITATION GROUP FOR THOSE AFFECTED BY AIDS

LIFE-LINK, a healing meditation group for those living with HIV infection, meets Thursday evening from 8:00 to 9:30pm at the Ministry Center for M.C.C. and Lazarus Ministries, located at the Friends’ Meeting House, 4836 Ellsworth Avenue, Shadyside.

Meetings consist of discussion based on the book, The Color of Light, and include experiences in guided meditation and visualization aimed toward wholeness and healing.

LIFE-LINK is facilitated by Richard D. Byrne, Director, Institute of Formative Spirituality, Duquesne University and Louis F. Kavar, Project Coordinator, Lazarus Ministries.

Those interested in attending LIFE-LINK should call 683-2994.

NEWS AND NOTES is published by the Pitt Men’s Study. All information and opinions are the sole responsibility of the Study and do not necessarily reflect the policies or views of the National Institutes of Health.