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Conference - 6/98 - COSSMHO [National Coalition of Hispanic Health and Human Services Organizations] (Puerto Rico)

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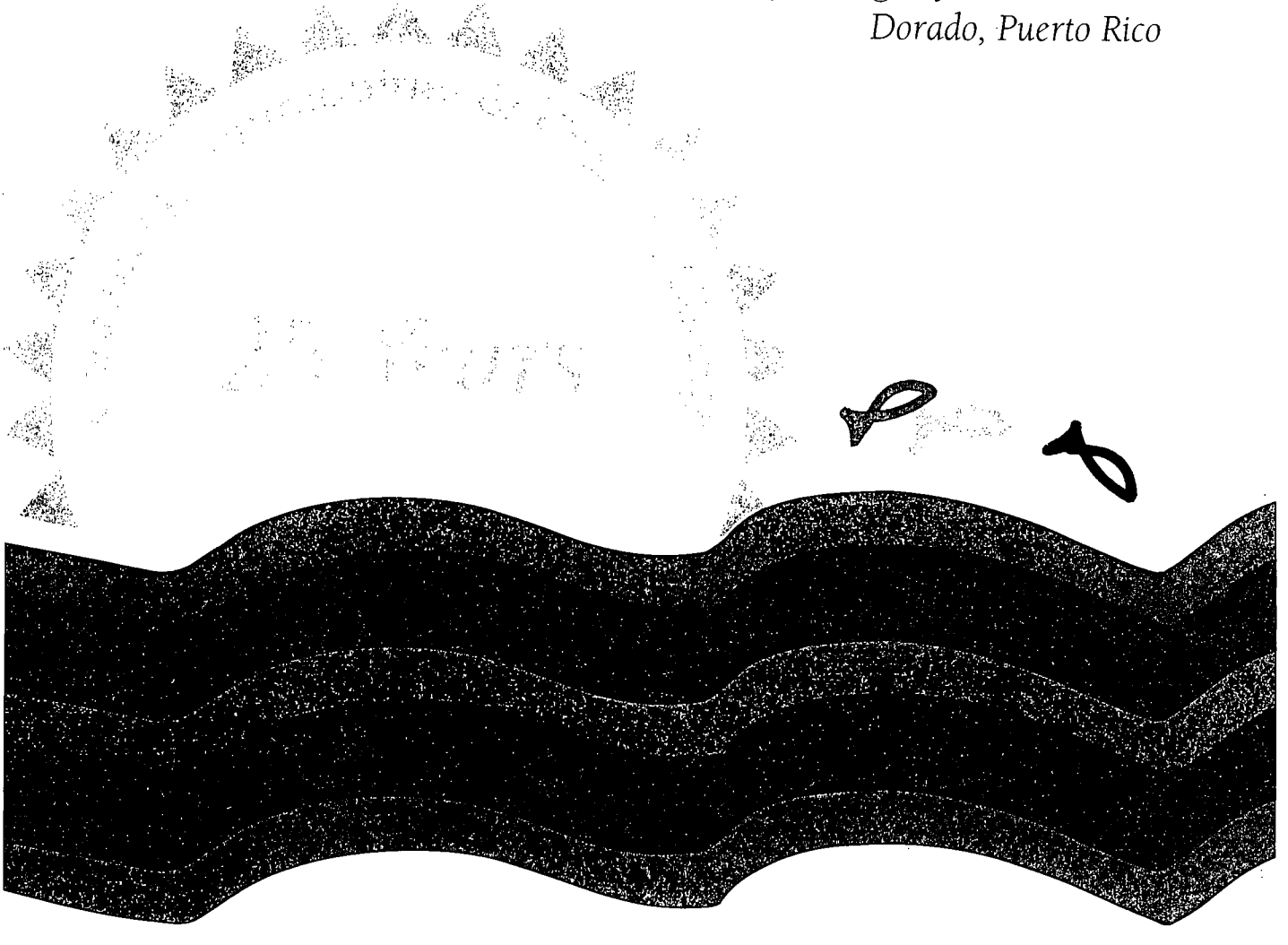
COSSMHO's Twelfth Biennial National Conference on Hispanic Health and Human Services

Conference Program

June 10-13, 1998

Hyatt Regency Cerromar Beach Hotel
Dorado, Puerto Rico



Start with bad news

- We are still many years from the end
- Growing sense of complacency
  - political indifference
  - public indifference
  - community exhaustion
  - individual complacency
- Demand for discretionary dollars rising
- Public and political malevolance
  - people of color
  - particularly immigrants
  - drug users
- Global epidemic spreading rapidly
  - 5.8 million new infections per year
  - 30 million living with HIV or AIDS
  - 40 million AIDS orphans by 2010
- HIV spreading most rapidly where resources are most limited
  - 90% of new infections in poorest nations
  - opportunity for access to treatments is virtually non-existent
  - $15,000/yr for PIs v. $5/yr. health spendin
  - even new AZT short-course is $80/year
- Vaccine is 10 years off at the earliest
- Here in US, no slow-down in rate of infections

- New adult AIDS cases are disproportionately among people of color
  - 15% white
  - 43% Black
  - 20% Latino

} 6/96 – 6/97

Now The good news

- New treatments helping thousands
  - AIDS deaths dropping, although not evenly
    - → down 33% for whites
    - → down 16% for blacks
    - → down 23% for latinos

    } '95 → '96
  - uneven access to treatments, even prophylaxis for basic OIs
    - → down 14% for whites
    - → down 4% for latinos
    - → stayed the same for blacks

    } '95 → '96
- improving the level and quality of supportive services to people of color
  - better local organizations
  - increased participation in planning
- still doing okay on Federal funding
  - $165 million increase for Ryan White
  - $150 million for drug treatment
  - NIH budget will double in 5 years

Agenda

- "Leading for Life" – progress toward unifying a Latino voice
  – need to keep the Hispanic caucus engaged
  - need to push for an allocation of resources based on where the epidemic *is*, not where it *was*
  - need to advocate for resources going to agencies by and from the communities most effected
  - must continue to advocate for supportive services *and* primary care
  - have to accept some of the social problems that continue to fuel the spread of HIV, especially *drugs*
  - must talk to young people, in a way that they understand, about sex and drugs
  - must take into account the diversity of the Latino and Hispanic communities
- surveillance

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Gerber Growing Plan Magnet

The Gerber Growing Plan

Questions Call 1-800-4-GERBER anytime day or night.

Gerber Growing Plan	When Is Baby Ready?	Did You Know?
  *Cereal/Juice: Basic foods for the first 2 years*	• Introduce single-grain cereal and single-ingredient juices when baby: – Weighs at least 13 lbs., has doubled birth weight – Is hungry after 8 to 10 breast feedings or drinks more than 32 ounces of formula a day • Also try multi-ingredient cereals and juice blends when baby has tried a variety of single-ingredient Gerber® 1ST FOODS® Baby Food	• Start with rice cereal as the very first food. • All Gerber® Dry Cereals provide iron, calcium and vitamin C, which are important for the first 2 years of life. • Juice is an easy way to teach new flavors. • All Gerber® Juices provide 100% of an infant's daily value of vitamin C.
1ST FOODS®   *Single Beginnings*	• Weighs at least 13 lbs., has doubled birth weight • Is hungry after 8 to 10 breast feedings or drinks more than 32 ounces of formula a day • Sits with support • Has control of head and body movements	• Puréed for easy swallowing and digestion. • Made without added sugar, salt, egg, milk, wheat and citrus. • Introduce single-ingredient foods one at a time to teach baby new tastes and to watch for possible allergic reactions.
2ND FOODS®   *Variety Building*	• Sits without support • Starts some form of crawling, scooting or rolling over • Eats from a spoon easily • Drinks from a sipper cup with help • Has control of head and body movements	• Smooth - textured foods. • Larger servings of favorite foods. • Offer dark green or yellow vegetables daily to be sure baby gets enough vitamin A for healthy eyes. • Try protein dishes such as Gerber® Meats and Gerber® Simple Recipe® Dinners for healthy growth & development.
3RD FOODS®   *Nutritional Variety*	• Sits alone easily • Mashes food with gums • Begins feeding self with fingers • Learns to crawl, pulls self to stand • Taste preferences begin to expand	• Larger portions to keep up with appetite. • Gentle seasoning and texture to encourage chewing. • Nutritional variety needed each day with the right texture and taste for your older baby. • Serve a variety daily to provide nutrition needed for healthy blood (iron), growth (zinc) and healthy gums (vitamin C).
  *Gerber® Graduates® Foods and Juices*	• Walks with help • Handles bite-sized foods and is learning to use a spoon • Has teeth and can bite through a variety of textures easily • Can drink all liquids from a sipper cup	• Finger foods that are easy for little hands to grasp. • Appropriate textures to help develop chewing skills. • Provide the protein, iron and vitamins your growing baby needs. • Handy jars, bowls and boxes ready to go when you're on the go.

54-87

COSSMHO

(National Coalition of Hispanic Health and Human Services Organizations)

Executive Director: Jane Delgado, Cuban, Republican.

COSSMHO's mantra is that they do NOT accept tobacco or alcohol money, and they are very vocal in criticizing those organizations which do.

There second mantra is that they are the only national organization focusing only on the health issues of Hispanics.

Considered a national leader in Hispanic health issues. Originally started as a national Hispanic mental health organizations. Has about 100 affiliates nationwide.

Has great access to the Secretary (HHS) and key members on the Hill.

In the past, has not always worked well with other Hispanic organizations, such as National Council of La Raza.

Staff is competent and dedicated.

Adolf Falcon is the director of public policy.

I believe Mary Thorgren is the head of health programs.

Two major HIV related programs:

1) CHATAN
2) SHAPE

CHATAN

Since 1993, funded by CDC to provide training and technical assistance on HIV an STD. Main HIV program is their CHATAN program -- Community HIV and AIDS Technical Assistance Network.

This network has 7 lead agencies, each with 10 - 12 subagencies, forming their network.

CHATAN focuses on needs assessments, implementation, evaluation, infrastructure development and programmatic capabilities. They also focus on financial management, training capabilities, computer training and grant writing.

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trained over 900 health professionals on the latest medical treatments, using a COSSMHO developed curriculum call *Protease Inhibitors: The Facts and Challenges*

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Currently under development, will have 4 lead agencies, with four more being added over the next two years.

Focus is on culturally competent means of disseminating prevention messages utilizing peer educators aimed at youth. Currently developing scripts.

OTHER ACTIVITIES:

Has a cooperative agreement with the Office of Minority Health to do various activities, not all related to AIDS.

> Cultural competence training of health professionals. More than 1,000 trained nationwide, focusing on programs and policy of organizations which affect access to care and treatment.
>
> Coordinated the Hispanic Health Summit sponsored by the DHHS last September. A National Conference focusing on customer service to Hispanics.

Treatment Update Talking Points

Focus on adherence issues and access to therapy issues.

Remind them that you are not a doctor.

There are more than 100 drugs on the market, and some 16 drugs of them are used in combination with protease inhibitors.

No one drug is right or wrong, and no combination is right or wrong. They should only be taken after discussing them and other options with your doctor or care giver.

On what basis are treatment decision made?

5 sets of guidelines are used to define the Standard of Care:

- Guidelines on Treatment of HIV Infection in Adults and Adolescents
- Pediatric Guidelines
- Opportunistic Infections Guidelines
- Perinatal Guidelines
- Hepatitis Antigen Guidelines

Remember, the goal of antiviral therapy is an undetectable viral load.

The key is to make sure that individuals are adhering to these guidelines and that doctors are educated on them, that patients are knowledgeable about them, and that patients are able to ask questions about their care.

Their role as case managers and others is to engage patients in discussions about treatments as a means to educate them, empower them and to enable them to have discussions with their health care provided.

You might want to ask yourself how are you being trained in this, and what it is you need to be doing to keep yourself up-to-date.

Look at community forums, the AIDS Education Training Centers, drug company forums, and university forums.

Remember, not everyone needs to be an expert on antiviral therapy, it is too complex. You just need to make sure that clinicians are aware of them and that your clients are gaining access to them, if that is what they want.

The Other Big Issue is How to Pay for Advances in Treatment

Where do people get the money to pay for treatment?

We know, through a COSSMHO report, that about 30% of Hispanics do NOT have health insurance

We know that from some research, Latinos present themselves for treatment later than non-Latinos, and this can affect the overall cost of treatment;

And we know, that for many Latinos, especially those who use the "air bridge" between the U.S. mainland and the Island, that continuity of care is an important factor.

Many people who need treatment rely on several major sources of funding:

Medicaid
ADAP
Compassionate use programs
Personal health insurance though their employer

More and more people are obtaining insurance through the use of health insurance continuity programs that extend insurance when lapsing due to unemployment and illness, including buying new insurance for people

(Might want to go over Vice President Gore's efforts to expand Medicaid and where we are on that.)

Triple drug combinations can be very expensive, as you all know.

Many ADAP program have waiting list, and some limit the formulary of drugs which can be covered.

(((As an aside, I won't go into the debate over whether treatment or prevention should be the priority in funding. They both should be. But that argument is occurring in Washington and at the state level, and it is one fir which we need to prepare ourselves.)))

The Issue of Adherence

What is really meant by adherence? Every drug, every day, at the same time, with no misses, ever? Is that feasible? Is it necessary?

A great survey recently came out which discussed just this specific issue, and as one might expect, there are various factors which affect adherence.

A newspaper article published this about two weeks ago went straight to the heart of adherence to drug therapy:

- 43% of HIV positive patients admitted to not taking their medications as prescribed,
- 54% of physicians treating HIV positive patients said that their patients do not follow their prescribed treatment protocols.
- the effectiveness of these new drug "cocktails" is dramatically reduced, not to say anything about the possibility of developing new strains of multi-drug resistant HIV.
- 93% of all patients understood that taking anti HIV drugs properly would prolong their lives.
- Nearly 1/4 of people in this survey admitted that they did not properly take their medications just one day earlier;
- Some 54% had missed doses or were otherwise non-compliant in the past month.
- Physicians estimated that some 6% of all HIV prescriptions are never even filled.
- Maybe even worse, the study indicates that those who have been HIV positive longer are the one's most likely to be non-compliant, taking drug holidays, as they are called.

What hinders adherence?

- complexity of taking the medication
- side effects
- timing
- wanting a "meds vacation"

What does not hinder adherence?

- Based on HRSA latest adherence conference call report (draft), socio-demographic factors (race, income, education) do not affect adherence.

- Thus, you cannot make decision on who will or will not take drugs based on race, education, etc.

Example: Ask them how many of them still have left over drugs from the last time they were sick. Now imagine having to do that every single day of your life with 3, 4 or 5 times as many drugs.

Case managers play a critical role in assisting clients with adherence.

Key things they can do to promote adherence:

- Remind them about taking drugs,
- Ask if they are having problems with them (side effects)
- Remind them to speak with their doctor if they are having problems to see if the medication can be changed.

Cultural and Linguistic Competency Issues in Treatment

One issue that I have not really discussed so far is that of cultural and linguistic appropriateness of the services being provided.

- How does this affect a person's access to and adherence to drug therapies.

- What cultural issues affect a person's willingness to continue to take drugs which may or may not have side affects, which may or may not affect their ability to work, or which may or may not affect their ability to live everyday lives.

- What effect does the Hispanic culture's lack of concern with death, or a least many Hispanic's belief in "**fatalismo**" (fatalism, or I am going to die anyway, it is just a part of living), or "**ni modo**" (I can't do anything about it), affect their willingness to adhere to safer sex practices, or their willing to take life prolonging drugs.

Some of this may be affected by the level of acculturation of an individual, but it can be a powerful force that care givers must be aware of in their interactions with Latinos.

These are the kind of questions that we need to be aware of in our work. These are the kind of questions that researchers need to be studying, and these are the kind of questions that our programs need to incorporate in their design.

I apologize for having more questions that answers, but questions are also very important.

Key HIV Treatment WEB Sites/Information Documents

http://www.hopkins-aids.edu/

http://www.fda.gov/oashi/aids/piindex.html

FDA backgrounder on Protease (dec 97)

http://www.projinf.org/fs/antiVirStrat.html

Project Inform discussion paper (Aug 97)

http://www.aegis.com/aegis/pubs/iapac/jn1997/combbk.html

(Sites are not endorsed by the White House)

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BAUER 0529

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National Coalition of Hispanic Health and Human Services Organizations

1501 Sixteenth Street, NW • Washington, DC 20036 • (202) 387-5000

May 19, 1998

Todd Summers
Deputy Director
White House Office of National AIDS Policy
736 Jackson Place, NW
Washington, D.C. 20503

Dear Mr. Summers:

We are pleased to invite you to be on a workshop panel at COSSMHO's Twelfth Biennial National Conference on Hispanic Health and Human Services to be held at the Hyatt Regency Cerromar Beach Hotel in Dorado, Puerto Rico from June 10-13, 1998. The information for your session is as follows:

Session title: HIV/AIDS Treatment Update
Day: Friday, June 12
Time: 10:15 - 11:45 a.m.

To accept this invitation, please complete the attached speaker confirmation form and return it to the attention of Maria Serrano by May 20, 1998. Our fax number is (202) 265-8027.

COSSMHO is pleased to provide you with a complimentary plenary breakfast on the day of your workshop as well as complimentary registration for workshops only for the entire conference. If you would like to register for any additional plenary sessions and meal functions, you can do so separately by completing the enclosed registration form.

If you have questions or need additional information, please call Maria Serrano at (202) 797-4327. We look forward to your participation at the conference.

Sincerely,

Jane Delgado /MS

Jane L. Delgado, Ph.D.

Enclosures

cc: Eliana Loveluck

CONFERENCE WORKSHOPS* AT A GLANCE

Thursday, June 11, 1998

10:15 am - 11:45 am
- Tackling Tobacco Together
- Reaching Hispanic Parents and Providers
- About Technology
- Making Sense of Welfare Reform
- The Experience of Hispanic Women and Breast Cancer

1:45 pm - 3:00 pm
- National Hispanic Colorectal Cancer Outreach and Education
- Strategies for Clean Air Efforts in Hispanic Communities
- *La Mujer*– A Status Report on Hispanic Women's Health Issues
- New Findings in Substance Abuse and Mental Health

3:15 pm - 4:30 pm
- Domestic Violence in Hispanic Communities
- HIV/AIDS Prevention for a New Generation
- Traffic Safety As a Component of Community Health
- Self Esteem in Young Latinas
- Immunization– Current and Future Issues

Friday, June 12, 1998

10:15 am - 11:45 am
- Culturally Competent Approaches to Outreach
- *Salud Para Todas*: A Community Education Program on Breast and Cervical Cancer
- HIV/AIDS Treatment Update
- Protecting Our Children–Monitoring the State Children's Health Insurance Program
- Getting the Data You Need: New Online Sources

1:45 pm - 3:00 pm
- Health in the New Millennium-A Radio Bilingüe Broadcast
- Developing and Evaluating Programs: Community Approaches
- Healthy People 2010– Shaping Up the Nation's Health Objectives
- Growing Up Hispanic–Where Are We Now?

3:15 pm - 4:30 pm
- Clinical Trials: Increasing Latino Representation
- Early Intervention for Developmental Disabilities: The Role of Culture, Community and Family Centered Values
- The Truth About Tobacco– As Told by COSSMHO's *Nuestras Voces* Youth
- Trends in Surveillance: HIV/AIDS, Diabetes, and Immunizations

Saturday, June 13, 1998

10:15 am - 11:30 am
- Innovative Immunization Community-Based Programs
- Language, Culture, and Health– Cultural Competency Training Program for Providers
- Diabetes: Addressing Risk Factors
- Mental Health and Depression in Hispanic Communities

11:45 am - 1:00 pm
- Talking About Sex
- The Water We Drink: Strategies for Clean Water in Hispanic Communities
- Managing Managed Care
- New Findings on Community Services for Hispanics

MANAGEMENT INSTITUTE WORKSHOPS

(Reserved for C.E.O.s and Senior Management of non-profit community-based organizations.)

Thursday, June 11, 1998

10:15 am - 11:45 am
- Managing Your Projects

1:45 pm - 3:00 pm
- Managing Your Money

3:15 pm - 4:30 pm
- Managing Your Staff

Saturday, June 13, 1996

10:15 am - 11:30 am
- Managing Technology

11:45 am - 1:00 pm
- Lobbying and the Law

LEADERSHIP ROUNDTABLES

Saturday, June 13, 1998

2:30 pm - 3:45 pm
- Health Care Access
- Welfare Reform
- Chronic Diseases
- Youth Issues
- Environmental Issues

* Preliminary titles and topics. Subject to change.

CONFERENCE SCHEDULE

Wednesday, June 10

3:30	pm	– 7:30	pm	General Registration
3:30	pm	– 6:00	pm	Exhibitor Set-Up
6:00	pm	– 8:30	pm	Opening Reception

Thursday, June 11

7:30	am	– 5:00	pm	Registration
8:00	am	– 5:00	pm	Exhibits Open
8:45	am	– 10:00	am	Plenary Breakfast
10:15	am	– 11:45	am	Workshops
12:00	pm	– 1:30	pm	Plenary Luncheon
1:45	pm	– 3:00	pm	Workshops
3:15	pm	– 4:30	pm	Workshops

Friday, June 12

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8:45	am	– 10:00	am	Plenary Breakfast
10:15	am	– 11:45	am	Workshops
10:15	am	– 11:45	am	OLASW Summit Meeting
12:00	pm	– 1:30	pm	Plenary Luncheon
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3:15	pm	– 4:30	pm	Workshops

Saturday, June 13

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8:00	am	– 2:30	pm	Exhibits Open
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10:15	am	– 11:30	am	Workshops
11:45	am	– 1:00	pm	Workshops
1:00	pm	– 2:15	pm	Lunch on Your Own
2:30	pm	– 3:45	pm	Leadership Roundtables
2:30	pm	– 4:30	pm	Exhibit Break Down
4:00	pm	– 5:00	pm	COSSMHO Membership Meeting
7:00	pm	– 12:00	am	Banquet by the Beach—Closing Dinner/Dance

AIR TRANSPORTATION

American Express Travel is the official travel agency for COSSMHO's Twelfth Biennial National Conference. You can reach them at 800-388-0095 or 202-393-2368. Let them know that you are with the COSSMHO conference, and they will work out your flight itinerary and mail your tickets to you. You will get a 10% discount off full coach fares and a 5% discount off discounted coach fares when flying American Airlines, the official airline for COSSMHO's conference (advance purchase necessary).

HOTEL

The conference will be held at the Hyatt Regency Cerromar Beach Hotel in Dorado, Puerto Rico. Please call 800-233-1234 or 787-796-1234 and make your reservation before May 8 to ensure availability. When calling, mention that you are with the COSSMHO conference to get these special rates for June 9th through the 13th. Please note: as a special benefit to conference attendees, these special rates will extend from three days before to three days after the conference.

Single Occupancy	$135.00
Double Occupancy	$135.00
Triple Occupancy	$180.00
Quadruple Occupancy	$180.00

These group guest room rates are subject to the appropriate government tax, which is presently 11 percent per room, per night occupied.

GROUND TRANSPORTATION

The Hyatt Regency Cerromar Beach is 22 miles west of San Juan, 45 minutes from the Luis Muñoz Marín Airport. You can take a Dorado Transport Coop shuttle for $15.00 each way (minimum of three passengers). You must mention you are with the COSSMHO conference to get this special rate. A shuttle representative holding a Hyatt Regency Cerromar Beach sign will be at the luggage pick-up area from 11:00 am to 10:00 pm everyday. If you plan to arrive before 11:00 am or after 10:00 pm, please make arrangements by calling Dorado Transport Coop at 787-796-1234 or 787-796-1214 (prices may vary for off-schedule pick-ups). Stop by the Dorado Transport Coop counter in the hotel lobby to arrange your departure from the hotel. If you decide to take a taxi, it will cost an average of $55.00 each way.

National Coalition of Hispanic Health and Human Services Organizations

1501 Sixteenth Street, NW • Washington, DC 20036 • (202) 387-5000

Facsimile Transmission

TO: Todd Summers
White House Office of National AIDS Policy

FROM: **Nadia Schomer**
CHATAN Deputy Project Director
1501 16th Street, NW
Washington, DC 20036
(202) 797-4337 Fax (202) 797-4353
E-mail: nschomer@cossmho.org

DATE: 5-19-98

Pages including cover 6 **Fax** (202) 456-2438 **Phone** (202) 456-2437

Attached please find a letter inviting you to present at COSSMHO's Twelfth Biennial National Conference on Hispanic Health and Human Services to be held in Dorado, Puerto Rico from June 10-13, 1998. I have included the invitation letter, a confirmation form, and the conference brochure. Please call me if you have any questions or if you need additional information.

PLEASE DELIVER IMMEDIATELY -- THANK YOU

25 YEARS OF CONNECTING COMMUNITIES AND CREATING CHANGE:
COSSMHO's 12th BIENNIAL NATIONAL CONFERENCE ON HISPANIC HEALTH AND HUMAN SERVICES
REGISTRATION FORM

This form may be copied. Use one form for each person registering. **Full payment must accompany form.** Please type or print your name and organization as you wish them to appear on your conference name badge.

Name *(First, Middle Initial, Last, Any Degrees)*		
Title		
Organization		
Street Address		
City	State	Zip Code
Telephone Number (Include Area Code)	FAX Number (Include Area Code)	E-Mail Address (optional)

Please circle one rate:	**Advance Registration** (By May 8, 1998)		**On-Site Registration**	
	Full Package*	Workshops Only**	Full Package*	Workshops Only**
Member (Organizational members may register up to five staff at this rate.)	$225	$135	$295	$175
New Member (This rate entitles to a free one-year COSSMHO membership.)	$250	$165	$325	$205
Non-Member	$350	$250	$475	$350
Student (Must submit valid proof of school enrollment, such as a copy of a current student identification card.)	$220	$130	$260	$170
Senior (Must submit valid proof—such as a copy of a driver's license—of being 65 years of age or older.)	$220	$130	$260	$170

***Full Package** rates include opening reception, three breakfast and two luncheon plenaries, and one banquet.
****Workshops Only** rates do not include meals or plenary sessions.

Registration: From the grid above, enter the amount of the registration package you selected: $_____

		Price	X Quantity	
Extra Plenary Meal Tickets: (List quantity of extra tickets ordered per meal event)	Breakfast	$25	_____	Amount $_____
	Lunch	$45	_____	Amount $_____
	Dinner/Dance	$90	_____	Amount $_____
				Total $_____

Registration: Please send registration form with a check or money order payable to **COSSMHO**. Mail to: COSSMHO Conference Office; 1501 Sixteenth Street, NW; Washington, DC, 20036. Phone: (202) 387-5000 Fax: (202) 265-8027

Confirmation: A postcard will be sent to you to confirm receipt of your registration form. Please bring the postcard along with identification to pick up your registration packet at the conference.

Cancellation: Notice of cancellation of advance registration must be received in writing no later than May 15, 1998. A $30.00 service charge will be deducted from each refund for cancellation. Absolutely no request for cancellation will be honored after May 15, 1998.

COSSMHO

25 Years of Connecting Communities & Creating Change

www.cossmho.org

FAX TRANSMISSION SHEET

To: Matthew Marquez

Date: 6/4/98 Fax: 202-456-2438

From: **Brenda L. Calhoun**
Administrative Assistant
Outreach Training & Technical Assistance
COSSMHO
National Coalition of Hispanic Health
and Human Services Organizations
1501 Sixteenth St., N.W.
Washington, DC 20036
(202)797-4332 Fax (202) 797-4353 E-mail - bcalhoun@cossmho.org

Pages to follow: 1 2 3 4 5 6 ___

Please deliver immediately!

Information for
Todd Summers presentation in PR.
We not have a available OMH summary,
You have to check with your office.
Thanks

If transmission was not successful or questions, please call Brenda Calhoun at (202) 797-4332

STAGE HIV AND AIDS PREVENTION AND EDUCATION (SHAPE)

PROJECT DESCRIPTION

In October 1997, COSSMHO was funded by the Centers for Disease Control and Prevention (CDC) Division of Adolescent and School Health (DASH) to conduct a five-year national demonstration project focusing on HIV/AIDS prevention among large populations of youths in high-risk situations. COSSMHO's **Stage HIV and AIDS Prevention and Education (SHAPE)** project is establishing a collaborative working relationships with community-based organizations (CBOs) and local health agencies in Hispanic communities across the country to serve as lead agencies in the implementation of the project. Four CBOs will participate during the project's first year, and two new CBOs will be added each ensuing year, for a total of 8 Hispanic communities by the end of the project period.

SHAPE is based on COSSMHO's "Theater as a Tool for Prevention" model which allows for a culturally competent means of disseminating prevention messages and promotes flexibility among local sites to adapt outreach mechanisms to the particular circumstances of each locality and the youth who live there. COSSMHO will work closely with local sites to recruit young people to participate in the theater troupe. Specific scripts will be developed with youth input and tailored to the target group in each community. After each performance, follow-up "booster" sessions will be implemented with youth audiences to reinforce messages conveyed earlier through the plays.

Summary of Accomplishments

- The completion of subcontracts with four lead agencies: Youth Development Inc. Albuquerque, New Mexico; Salud Para La Gente, Watsonville, California; Association for the Advancement of Mexican Americans, Houston, Texas; and Fundación SIDA, San Juan, Puerto Rico.

- The preparation of site budgets as requested by the CDC. These budgets include a detailed description of site activities for the first year of the project.

- The preparation of the preliminary nomination list for an eight member National Advisory Committee. This committee will be charged with advising COSSMHO and the sites about project implementation issues, as well as assisting in the development of materials to be used by sites as guidance in creating plays and other educational materials.

- The preparation of preliminary scripts and background information to be provided to the four sites.

CHATAN
Community HIV and AIDS Technical Assistance Network

PROJECT DESCRIPTION

In 1993, COSSMHO was funded by the Centers for Disease Control and Prevention (CDC) for a 5-year project to provide training and technical assistance to agencies serving Hispanics at high risk for HIV infection and sexually transmitted diseases (STDs). COSSMHO's **Community HIV and AIDS Technical Assistance Network (CHATAN)** has established a collaborative working relationship with CBOs across the country to serve as lead agencies in the implementation of the project. The **lead agencies** are located in: Arizona, California, District of Colombia, New Mexico, New York, Puerto Rico, and Texas. Each of the seven lead agencies also collaborate with an additional 10-12 organizations--including state and local health departments--providing services to Hispanics. These additional 80 organizations are referred to as **prevention partners.**

CHATAN activities focus on providing targeted, agency-specific training and technical assistance based on priorities identified in detailed needs assessments. These areas include the development, implementation, and evaluation of prevention programs, and organizational capacity building designed to improve infrastructure and programmatic capabilities. Training and technical assistance activities have addressed strategic planning, financial management, training capabilities, computer capabilities, and grant writing. Of the seven original CHATAN lead agencies, three became recipients of CDC's Direct Funding for Community Based Organizations (in HIV/AIDS prevention) during 1997.

Summary of Accomplishments

- CHATAN conducted an HIV treatment project which trained over 900 health professionals on the latest medical treatments available for people living with HIV/AIDS. The lead agencies participated in a Training of Trainers using COSSMHO's curriculum entitled **Protease Inhibitors: The Facts and Challenges of a Health Care Breakthrough** and replicated the training in their own communities.

- CHATAN is currently finalizing two curricula: **HIV/STD Prevention: Designing Effective Programs for Hispanics**, and the **HIV/AIDS Parent Education Workshop**, which provides Hispanic parents with basic HIV/AIDS prevention information and strategies for communicating these with their children and adolescents.

- CHATAN has published **HIV/AIDS: The Impact on Hispanics**, which contains up-to-date data, information, and tools to expand advocacy on behalf of Hispanic communities in preventing HIV/AIDS. The **La Tardeada** Video and Discussion Guide, which target migrant Hispanic youth with HIV/AIDS information and prevention messages, have also been completed.

- CHATAN is currently developing the **Workbook on Management of HIV/AIDS Prevention Programs**, designed as a self-study guide for CBOs to increase agency staff knowledge of management issues specific to HIV/AIDS prevention and culturally competent service delivery. CHATAN also develops **Technical Assistance Packages** and **Technical Assistance Memos** on topics related to technical assistance needs of HIV/AIDS prevention program implementation.

- CHATAN also conducts workshops specific to HIV/AIDS during COSSMHO's National Biennial Conferences.

Treatment Update Talking Points

Focus on adherence issues and access to therapy issues.

Remind them that you are not a doctor.

There are more than 100 drugs on the market, and some 16 drugs of them are used in combination with protease inhibitors.

No one drug is right or wrong, and no combination is right or wrong. They should only be taken after discussing them and other options with your doctor or care giver.

On what basis are treatment decision made?

5 sets of guidelines are used to define the Standard of Care:

- Guidelines on Treatment of HIV Infection in Adults and Adolescents
- Pediatric Guidelines
- Opportunistic Infections Guidelines
- Perinatal Guidelines
- Hepatitis Antigen Guidelines

TALKING POINTS

Remember, the goal of antiviral therapy is an undetectable viral load.

The key is to make sure that individuals are adhering to these guidelines and that doctors are educated on them, that patients are knowledgeable about them, and that patients are able to ask questions about their care.

Their role as case managers and others is to engage patients in discussions about treatments as a means to educate them, empower them and to enable them to have discussions with their health care provided.

You might want to ask yourself how are you being trained in this, and what it is you need to be doing to keep yourself up-to-date.

Look at community forums, the AIDS Education Training Centers, drug company forums, and university forums.

Remember, not everyone needs to be an expert on antiviral therapy, it is too complex. You just need to make sure that clinicians are aware of them and that your clients are gaining access to them, if that is what they want.

The Other Big Issue is How to Pay for Advances in Treatment

Where do people get the money to pay for treatment?

We know, through a COSSMHO report, that about 30% of Hispanics do NOT have health insurance

We know that from some research, Latinos present themselves for treatment later than non-Latinos, and this can affect the overall cost of treatment;

And we know, that for many Latinos, especially those who use the "air bridge" between the U.S. mainland and the Island, that continuity of care is an important factor.

Many people who need treatment rely on several major sources of funding:

Medicaid
ADAP
Compassionate use programs
Personal health insurance though their employer

More and more people are obtaining insurance through the use of health insurance continuity programs that extend insurance when lapsing due to unemployment and illness, including buying new insurance for people

(Might want to go over Vice President Gore's efforts to expand Medicaid and where we are on that.)

Triple drug combinations can be very expensive, as you all know.

Many ADAP program have waiting list, and some limit the formulary of drugs which can be covered.

(((As an aside, I won't go into the debate over whether treatment or prevention should be the priority in funding. They both should be. But that argument is occurring in Washington and at the state level, and it is one fir which we need to prepare ourselves.)))

The Issue of Adherence

What is really meant by adherence? Every drug, every day, at the same time, with no misses, ever? Is that feasible? Is it necessary?

A great survey recently came out which discussed just this specific issue, and as one might expect, there are various factors which affect adherence.

A newspaper article published this about two weeks ago went straight to the heart of adherence to drug therapy:

- 43% of HIV positive patients admitted to not taking their medications as prescribed,
- 54% of physicians treating HIV positive patients said that their patients do not follow their prescribed treatment protocols.
- the effectiveness of these new drug "cocktails" is dramatically reduced, not to say anything about the possibility of developing new strains of multi-drug resistant HIV.
- 93% of all patients understood that taking anti HIV drugs properly would prolong their lives.
- Nearly 1/4 of people in this survey admitted that they did not properly take their medications just one day earlier;
- Some 54% had missed doses or were otherwise non-compliant in the past month.
- Physicians estimated that some 6% of all HIV prescriptions are never even filled.
- Maybe even worse, the study indicates that those who have been HIV positive longer are the one's most likely to be non-compliant, taking drug holidays, as they are called.

What hinders adherence?

- complexity of taking the medication
- side effects
- timing
- wanting a "meds vacation"

What does not hinder adherence?

- Based on HRSA latest adherence conference call report (draft), socio-demographic factors (race, income, education) do not affect adherence.

- Thus, you cannot make decision on who will or will not take drugs based on race, education, etc.

Example: Ask them how many of them still have left over drugs from the last time they were sick. Now imagine having to do that every single day of your life with 3, 4 or 5 times as many drugs.

Case managers play a critical role in assisting clients with adherence.

Key things they can do to promote adherence:

- Remind them about taking drugs,
- Ask if they are having problems with them (side effects)
- Remind them to speak with their doctor if they are having problems to see if the medication can be changed.

Cultural and Linguistic Competency Issues in Treatment

One issue that I have not really discussed so far is that of cultural and linguistic appropriateness of the services being provided.

- How does this affect a person's access to and adherence to drug therapies.

- What cultural issues affect a person's willingness to continue to take drugs which may or may not have side affects, which may or may not affect their ability to work, or which may or may not affect their ability to live everyday lives.

- What effect does the Hispanic culture's lack of concern with death, or a least many Hispanic's belief in "**fatalismo**" (fatalism, or I am going to die anyway, it is just a part of living), or "**ni modo**" (I can't do anything about it), affect their willingness to adhere to safer sex practices, or their willing to take life prolonging drugs.

Some of this may be affected by the level of acculturation of an individual, but it can be a powerful force that care givers must be aware of in their interactions with Latinos.

These are the kind of questions that we need to be aware of in our work. These are the kind of questions that researchers need to be studying, and these are the kind of questions that our programs need to incorporate in their design.

I apologize for having more questions that answers, but questions are also very important.