Houston Area HIV Services Ryan White Planning Council

Affected Community Committee Meeting

12 noon, Monday, August 21, 2017 Meeting Location: 2223 West Loop South, Room 416 Houston, TX 77027

AGENDA

I. Call to Order

- A. Welcome
- B. Announce who will be chairing the meeting
- C. Moment of Reflection
- D. Adoption of the Agenda
- E. Approve the Minutes

II. Public Comment

(NOTE: If you wish to speak during the Public Comment portion of the meeting, please sign up on the clipboard at the front of the room. No one is required to give his or her name or HIV status. All meetings are audio taped by the Office of Support for use in creating the meeting minutes. The audiotape and the minutes are public record. If you state your name or HIV/AIDS status it will be on public record. If you would like your health status known, but do not wish to state your name, you can simply say: "I am a person living with HIV", before stating your opinion. If you represent an organization, please state that you are representing an agency and give the name of the organization. If you work for an organization, but are representing yourself, please state that you are attending as an individual and not as an agency representative. Individuals can also submit written comments to a member of the staff who would be happy to read the comments on behalf of the individual at this point in the meeting.)

III. Old Business

- A. Camino hacia tu Salud
 - 5:00 pm set up, Monday, August 28, 2017 at Leonel Castillo Comm. Center
 - Topics: Case Management; ADAP Updates and We Are Listening
 - Volunteers: Isis, Tana, Skeet, Curtis, Teresa, Tracy, Alex, Evelio & Steven
- B. Road 2 Success -10 am -2 pm, Sat. Nov. 4th at the Montrose Center
 - Suggested workgroup topics from Needs Assessment Amber Harbolt
 - Brain storm re: workgroup topics
- C. Community Events
- D. Greeters

IV. Training: Standards of Care and Performance Measures

- V. Announcements September meeting: Consumer-only workgroup meeting Petty Cash Announcement - Tori
- VI. Adjourn
- VII. Members meet with committee mentor

Rodney Mills and Tana Pradia, Co-Chairs

Amber Harbolt

A11

Teresa Pruitt

Houston Area HIV Services Ryan White Planning Council

Affected Community Committee Meeting

12 noon, Monday, July 24, 2017 Meeting Location: 2223 West Loop South, Room 240, Houston, TX 77027

MINUTES

MEMBERS PRESENT	MEMBERS ABSENT	OTHERS PRESENT
Tana Pradia, Co-Chair	Amber David	Cecilia Ross, RWPC Chair
Rodney Mills, Co-Chair	Arlene Johnson	
Curtis Bellard	John Poole	Ryan White Grant Administration
Skeet Boyle	Alex Moses	Tasha Traylor
Tracy Gorden		
Herman Finley		Office of Support
Denis Kelly		Tori Williams
Allen Murray		Rod Avila
Teresa Pruitt		
Veria Steptoe		

Call to Order: Pradia called the meeting to order at 12:04 p.m. and asked for a moment of reflection.

Adoption of the Agenda: <u>Motion #1</u>: it was moved and seconded (Bellard, Boyle) to adopt the agenda. Motion carried unanimously.

Approval of the Minutes: <u>Motion #2</u>: it was moved and seconded (Bellard, Kelly) to approve the June 19, 2017 minutes. **Motion carried.** Abstentions: Pruitt.

Public Comment: None.

Old Business

Update on Pride Festival: Pradia reported that the information booth at the event went well despite the rain at the beginning of the day. Pradia recommended participation in the festival again next year. Volunteers felt that it would be helpful to have small 'give-aways' for festival attendants to get more visitors to stop by the booth.

Road 2 Success: Williams thanked those who helped with the event and reported that Road 2 Success at Thomas Street Health Center was a success. Over 49 people attended and the presentations by the case managers were excellent. According to participants, the 'We are Listening' portion of the program was very interactive.

Camino hacia Tu Salud: Williams went over the event details for the August 28, 2017 *Camino hacia Tu Salud*. Topics are still to be determined but will probably include an ADAP update.

Community Events: Ross provided details for the October 2017 Miss Utopia Pageant. Boyle volunteered to be the point person for the event.

Greeters: Committee members signed up to be greeters at 2017 Council meetings.

Announcements: Williams announced upcoming meeting dates and trainings related to Standards of Care workgroup meetings. All are welcome to attend. Ross announced the Committee Cross Training dates and encouraged all to attend. Gorden reminded volunteers for the Project LEAP graduation to be sure to arrive for set up at 4:00 pm.

Adjourn: The meeting adjourned at 12:39 p.m.

Submitted by:

Approved by:

Tori Williams, Director

Date

Committee Chair

Date

Affected Community Committee 2017 Community Events (as of 07/25/17)

Point Person (PP): Committee member who picks up display materials and returns them to the Office of Support.

Day, date, times	Event	Location	Participants
Sunday, March 5 1pm-Walk	AIDS Foundation Houston (AFH) AIDS Walk	Houston Park Downtown 1100 Bagby Street, 77002	Allen Murray will distribute Project LEAP flyers.
Saturday, June 24 Noon – 7:00 pm	Pride Festival	Downtown near City Hall	Shift 1 (11:30 am-2 pm): PP Tracy G, Tana, Steven V. Shift 2 (2-4:30 pm) Alex, Allen, Isis Shift 3 (4:30-7 pm): PP: John P., Rodney, Alex
Thursday, June 29 11:30 am – 2 pm	Road 2 Success	Thomas Street Health Center 2015 Thomas Street, 77009	Need 5 Volunteers: Curtis, Cecilia, Teresa, Denis, Isis and Alex.
Monday, August 28 5 pm – 8 pm	Camino hacia tu Salud	Positive713 Leonel Castillo Community Center 2101 South Street, 77009	<u>Need 7 Volunteers:</u> Isis, Tana, Skeet, Curtis, Teresa, Tracy, Alex, Steven and Evelio
Sunday, October 22	MISS UTOPIA	Crowne Plaza Northwest-Brookhollow 12801 Northwest Freeway Houston, TX 77040	Volunteers: PP: <u>Skeet</u> , Curtis, Alex, Isis, Cecilia, Tana DISTRIBUTE LEAP FLYERS
Saturday, November 4	Road 2 Success	Montrose Center 401 Branard Street, 2 nd Floor, 77006	Need 12 volunteers
Tuesday, December 1	World AIDS Day Events		Most committee members attend events DISTRIBUTE LEAP FLYERS
Saturday in Nov. or Dec. Date TBD	Camino hacia tu Salud	Tentative: Leonel Castillo Community Ctr. 2101 South Street, 77009	Need 8 Spanish Speaking Volunteers: DISTRIBUTE LEAP FLYERS
Saturday in January	Road 2 Success	Montrose Center 401 Branard Street, 2 nd Floor, 77006	<u>Need 10 Volunteers (incl. Spanish</u> <u>speaking):</u>
			DISTRIBUTE LEAP FLYERS

You are invited to a *consumer-only* workgroup to discuss **Standards of Care and Performance Measures**

for Ryan White funded HIV/AIDS services

Examples of services to be discussed:

- ✓ Primary Medical Care
- 🗸 Case Management
- 🗸 Dental Care
- \checkmark Local Pharmacy Assistance
- ✓ Professional Counseling
- \checkmark Transportation
- Medical Nutritional Therapy & Supplements

<u>Standards of Care</u> are the minimal acceptable levels of quality in service delivery based upon accepted industry guidelines and practices. Houston area standards relate to issues such as staff training and supervision, client rights and confidentiality, timeliness of service



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Harris County Annex 83 2223 West Loop South, Room 416 Houston, Texas 77027

delivery, allowable activities, the minimum services each client should receive, and more.

Performance Measures indicate to what extent a service has achieved its desired outcomes. Examples of Houston area performance measures include: health status (such as viral load and CD4 increases and decreases), quality of life, cost-effectiveness, adherence to treatment and more.



To review the current Standards of Care and Performance Measures, please go to: <u>http://rwpchouston.org/Publications/SOCandPM.htm</u>

> For more information contact: Tori Williams Ryan White Planning Council Office of Support 713 572-3724 or victoria.williams@cjo.hctx.net

FOR THOSE NEEDING TRANSLATION SERVICES: If you need an ASL or Spanish interpreter, please call to request an interpreter at least two days in advance: 713 572-2813 (TTY) or 713 572-3724 (Main)

Usted está invitado/a a un *grupo de trabajo orientado al consumidor* a dialogar sobre Normas del Cuidado y Medidas de Resultados Para los Servicios del VIH/SIDA financiados por Ryan White

Ejemplos de Servicios a ser discutidos:

- Cuidado médico primario
- ✓ Administración de Casos
- ✓ Cuidado Dental
- ✓ Asistencia en Farmacia
- ✓ Servicios de salud mental
- ✓ Transporte
- ✓ Suplementos nutricionales

Normas del Cuidado: es el mínimo nivel de calidad aceptable en la entrega de los servicios, basados en reconocidas prácticas y directrices industriales. Las Normas del Cuidado en el área de Houston se relacionan a temas como: entrenamiento y supervisión del



Lunes, Septiembre 25, 2017 12:00 p.m. – Consumer Workgroup

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personal, derechos y confidencialidad del cliente; exactitud en la entrega de servicios, actividades aprobadas; servicios mínimos que el cliente pueda recibir y otros temas.

<u>Medidas de Rendimiento</u>: indica a qué extensión un servicio ha logrado el resultado deseado. Ejemplos en el área de Houston incluyen: estado de salud (tales como carga viral e incremento o disminución del CD4); calidad de vida; eficacia de costo; adhesión al tratamiento y otros temas.



Para revisar la actual Normas del Cuidado y Medidas de Rendimiento, favor de ir a: <u>http://rwpchouston.org/Publications/SOCandPM.htm</u>

> Para mayor información llame: Ryan White Planning Council Office of Support 713 572-3724

PARA PERSONAS QUE NECESITEN INTERPRETACION: Si necesita un intérprete, por favor llame al 713 572-3724 por lo menos 48 horas antes.



Your source for the latest research news

ART: New injectable antiretroviral treatment proved to be as effective as standard oral therapy

Date: August 3, 2017

Source: IDIBELL-Bellvitge Biomedical Research Institute

Summary: A new clinical trial concludes that intramuscular administration of antiretrovirals every 4 or 8 weeks gets results similar to daily pill intake, shows research. Spacing drug intake would lead to greater adherence to treatment and an improved quality of life for HIV patients, add investigators.

FULL STORY

Antiretroviral therapy (ART) intramuscularly administered may have the same effectiveness as current oral treatments. This is the main conclusion of the Phase II clinical trial carried out by 50 centers around the world -- 9 in Spain -- to which the team of Dr. Daniel Podzamczer, principal investigator of the Bellvitge Biomedical Research Institute (IDIBELL) and Chief of the HIV and STD Unit of the Infectious Diseases Service of Bellvitge University hospital (HUB) has contributed. The results of the trial, published by the journal *The Lancet*, pave the way to the implantation of all-injectable antiretroviral therapies with a lower frequency of administration, which would imply a significant improvement of the quality of life of HIV patients.

In the study, which involved 286 patients with previously suppressed viral loads, the effectiveness of the combination of carbotegravir -- a new inegrase inhibitor -- and rilpivirine -- a no nucleoside -- injected intramuscularly every 4 or 8 weeks was tested in comparison to standard maintenance therapy, which includes three orally-administered drugs: carbotegravir and abacavir -- lamivudine.

"This is the first time that all-injectable ART has been used in a trial; In addition, it consists of only 2 drugs, something that is not new but that supports the paradigm shift of 3 to 2 drugs in some virologically suppressed patients," says Dr. Podzamczer. The injected drugs are nanoparticles, which allows them to have a longer half-life of several weeks.

After 96 weeks, researchers found that 87% of patients in the group treated every 4 weeks and 94% in the one treated every 8 weeks maintained viral load suppression, a better figure than the one achieved in the standard oral treatment group, a 84%.

"With HIV, we are at a point of chronification of the disease; in a few years we have moved from giving 14 pills a day to one or two, but it is still a daily treatment that requires strict compliance. Therefore, spacing drug administration to once every month or every two months will potentially translate into improved adherence rates and improved quality of life for patients," explains Dr. Podzamczer.

At the same time, the levels of satisfaction of the participating patients were also evaluated; at the end of the trial,

about 90% of patients in the groups treated intramuscularly were very satisfied with the idea of continuing with this type of treatment.

At the moment, participating centers and research teams are already working on the development of a new Phase III clinical trial that corroborates the results in terms of efficacy, safety and tolerability for both injectable treatments, every 4 and every 8 weeks.

Story Source:

Materials

provided by **IDIBELL-Bellvitge Biomedical Research Institute**. *Note: Content may be edited for style and length.*

Journal Reference:

 David A Margolis, Juan Gonzalez-Garcia, Hans-Jürgen Stellbrink, Joseph J Eron, Yazdan Yazdanpanah, Daniel Podzamczer, Thomas Lutz, Jonathan B Angel, Gary J Richmond, Bonaventura Clotet, Felix Gutierrez, Louis Sloan, Marty St Clair, Miranda Murray, Susan L Ford, Joseph Mrus, Parul Patel, Herta Crauwels, Sandy K Griffith, Kenneth C Sutton, David Dorey, Kimberly Y Smith, Peter E Williams, William R Spreen. Longacting intramuscular cabotegravir and rilpivirine in adults with HIV-1 infection (LATTE-2): 96-week results of a randomised, open-label, phase 2b, non-inferiority trial. *The Lancet*, 2017; DOI: 10.1016/S0140-6736(17)31917-7

Cite This Page:	Μ	1LA	APA	Chicago

IDIBELL-Bellvitge Biomedical Research Institute. "ART: New injectable antiretroviral treatment proved to be as effective as standard oral therapy." ScienceDaily. ScienceDaily, 3 August 2017. </www.sciencedaily.com/releases /2017/08/170803091942.htm>.

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Your source for the latest research news

Child living with HIV maintains remission without drugs since 2008 Child treated in infancy

Date:	July 24	2017
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Source: NIH/National Institute of Allergy and Infectious Diseases

Summary: A nine-year-old South African child who was diagnosed with HIV infection at one month of age and received anti-HIV treatment during infancy has suppressed the virus without anti-HIV drugs for eight and a half years, scientists report. This case appears to be the third reported instance of sustained HIV remission in a child after early, limited anti-HIV treatment.

FULL STORY



Researchers have renewed hope to learn how to induce longterm HIV remission in infected babies.

Credit: © designer491 / Fotolia

A nine-year-old South African child who was diagnosed with HIV infection at one month of age and received anti-HIV treatment during infancy has suppressed the virus without anti-HIV drugs for eight and a half years, scientists reported today at the 9th IAS Conference on HIV Science in Paris. This case appears to be the third reported instance of sustained HIV remission in a child after early, limited anti-HIV treatment.

Previously, the "Mississippi Baby," born with HIV in 2010, received anti-HIV treatment beginning 30 hours after birth, stopped therapy around 18 months of age, and controlled the virus without drugs for 27 months before it reappeared in her blood. In 2015, researchers reported that a French child who was born with HIV in 1996, started anti-HIV therapy at age 3 months, and stopped treatment sometime between ages 5.5 and 7 years continued to control the virus without drugs more than 11 years later.

"Further study is needed to learn how to induce long-term HIV remission in infected babies," said Anthony S. Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH). "However, this new case strengthens our hope that by treating HIV-infected children for a brief period beginning in infancy, we may be able to spare them the burden of life-long therapy and the health consequences of long-term immune activation typically associated with HIV disease."

NIAID funded the clinical trial in which the child received treatment and follow-up monitoring.

The South African child whose case was reported today was definitively diagnosed with HIV infection in 2007 at 32 days of age, and then was enrolled in the NIAID-funded Children with HIV Early Antiretroviral Therapy (CHER) clinical trial. HIV-infected infants in the trial were assigned at random to receive either deferred antiretroviral therapy (ART) or early, limited ART for 40 or 96 weeks. The current child was assigned to the group of 143 infants who received early ART for 40 weeks.

Before starting treatment, the child had very high levels of HIV in the blood (viral load), but after beginning ART at about 9 weeks of age, treatment suppressed the virus to undetectable levels. Investigators halted treatment after 40 weeks and closely monitored the infant's immune health, and the child has remained in good health during years of follow-up examinations. Although it was not standard practice in South Africa to monitor viral load in people who were not on ART, recent analyses of stored blood samples taken during follow-up showed that the child has maintained an undetectable level of HIV.

When the child was 9-and-a-half years old, investigators conducted thorough laboratory and clinical studies to assess the child's immune health and the presence of HIV. The scientists detected a reservoir of virus integrated into a tiny proportion of immune cells, but otherwise found no evidence of HIV infection. The child had a healthy level of key immune cells, a viral load that was undetectable by standard assays, and no symptoms of HIV infection. The researchers detected a trace of immune system response to the virus, but found no HIV capable of replicating. The scientists also confirmed that the child does not have genetic characteristics associated with spontaneous control of HIV, suggesting that the 40 weeks of ART provided during infancy may have been key to achieving HIV remission.

"To our knowledge, this is the first reported case of sustained control of HIV in a child enrolled in a randomized trial of ART interruption following treatment early in infancy," said Avy Violari, F.C.Paed. Dr. Violari co-led the study of the case reported today as well as the CHER trial with Mark Cotton, M.Med., Ph.D. Dr. Violari is head of pediatric research at the Perinatal HIV Research Unit, part of the University of the Witwatersrand in Johannesburg. Dr. Cotton is head of the division of pediatric infectious diseases and director of the family infectious diseases clinical research unit at Stellenbosch University, South Africa.

"We believe there may have been other factors in addition to early ART that contributed to HIV remission in this child," said Caroline Tiemessen, Ph.D., whose laboratory is studying the child's immune system. "By further studying the child, we may expand our understanding of how the immune system controls HIV replication." Dr. Tiemessen is head of cell biology at the Centre of HIV and STIs of the National Institute of Communicable Diseases (NICD) in Johannesburg.

An ongoing NIH clinical trial called IMPAACT P1115 is testing the hypothesis that giving ART to HIV-infected newborns beginning within 48 hours of birth may permit long-term control of HIV replication after treatment is stopped, potentially leading to HIV remission. IMPAACT P1115 began in 2014 and has enrolled close to 400 HIV-exposed infants, 42 of whom are HIV infected, in Argentina, Brazil, Haiti, Malawi, South Africa, Uganda, the United States, Zambia and Zimbabwe. The first children may become eligible to stop ART in late 2017.

NIAID provided funding for the CHER trial as part of a Comprehensive International Program for Research on AIDS-South Africa grant. Additional support was provided by the Medical Research Council Clinical Trials Unit at University College London, the Departments of Health of the Western Cape and Gauteng in South Africa, and ViiV Healthcare. The *Eunice Kennedy* Shriver National Institute of Child Health and Human Development, also part of NIH, supported continued observation of the children in CHER after the study ended. The EPIICAL Consortium funded the recent analysis of viral load in the children who participated in CHER. The South African Research Chairs Initiative of the Department of Science and Technology and the National Research Foundation of South Africa funded the laboratory studies of the child whose case was reported today.

Reference: A Violari *et al.* Viral and host characteristics of a child with perinatal HIV-1 following a prolonged period after ART cessation in the CHER trial. 9th IAS Conference on HIV Science, Paris (2017).

Story Source:

Materials

provided by **NIH/National Institute of Allergy and Infectious Diseases**. Note: Content may be edited for style and length.

Cite This Page:

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NIH/National Institute of Allergy and Infectious Diseases. "Child living with HIV maintains remission without drugs since 2008: Child treated in infancy." ScienceDaily. ScienceDaily, 24 July 2017. <www.sciencedaily.com/releases /2017/07/170724105054.htm>.

RELATED STORIES

Effectiveness of New Anti-HIV Medication to Protect Women and Infants Demonstrated

Aug. 1, 2016 — Each year, 1.5 million women living with HIV become pregnant. Without effective treatment, up to 45 percent of HIV-infected mothers will transmit the virus to their child, usually through ... **read more** »



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