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00:37:33
                Ben Collins:
                                Ben Collins, ReShape and EATG hello
everyone.
                Olivia G Ford (she/they) - The Well Project:
00:37:58
morning to all from Brooklyn, New York, USA! Olivia G Ford, she/they,
The Well Project 💗
00:38:23
                Bridgette Picou:
                                        Good Morning, Bridgette Picou,
The Well Project
00:38:28
                Julie Patterson:
                                        Good morning from sunny
Cleveland, Ohio, USA!
                Charles Chinguwo:
                                        Hi, I'm an AI assistant
00:38:55
helping Charles innocent Chinguwo take notes for this meeting. Follow
along the transcript here: https://otter.ai/u/
yf3nYIMLrbzPkVnFQ0klRk7LS7E?utm_source=va_chat_link_1
You'll also be able to see screenshots of key moments, add highlights,
comments, or action items to anything being said, and get an automatic
summary after the meeting.
                                Hi all! Cosette Audi from the
00:39:24
                Cosette Audi:
Elizabeth Glaser Pediatric AIDS Foundation. Based in DC, currently
calling in from Ohio, USA
00:40:17
                Daniel D. Driffin, DrPH:
                                               Daniel D. Driffin -
HIV Vaccine Trials Network, USA
00:41:04
                Jim Pickett:
                                210 people are registered for this
session today!
00:41:12
                Larry Bryant:
                                Good morning! Larry Bryant (he, him),
Senior Program Manager with The Reunion Project. Also, a 38 year
survivor of HIV living in Brooklyn
                Shekinah Rose: Good morning Shekinah Rose from
00:41:35
Pittsburgh PA, Positively Trans
                Jim Pickett:
00:41:43
                                Have you introduced yourself?
00:41:49
                Udom Likhitwonnawut:
                                        Good morning to all. I am Udom
Likhitwonnawut from Chiang Mai, Thailand. Welcome to the breakfast
club.
00:41:51
                                I am! Good morning everyone and good
                victor reves:
morning to my Thrivers!!
00:41:51
                Patricia Segura:
                                        Patricia Segura, HVTN PM
00:42:08
                Shekinah Rose: 39 years living with HIV/AIDS
                Wakefield Steven:
00:42:40
                                        Wakefield, Seattle,
Washington, USA
00:42:54
                Darren Lauscher:
                                        39 years as well living with
HIV/AIDS
                                "lifetime thrivers" - such great
00:43:02
                Jim Pickett:
language — I am stealing it too
                Ronald Johnson: Ronald Johnson, U.S. People Living
00:43:12
With HIV Caucus
00:43:28
                Supattra Rungmaitree:
                                        Supattra, Bangkok, Thailand
00:44:12
                Barbara Friedland:
                                        Barbara Friedland, Population
Council, NY, NY
00:44:20
                vuyolwethu magasana:
                                        Vuyo, Durban South Africa
00:44:22
                Kevin Herwig: Kevin Herwig, HIV+Hepatitis Policy
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Institute, Washington DC USA Replying to "Barbara Friedland, P..." 00:44:28 Jim Pickett: You made it! 00:44:48 Félicitations, peuple de France, pour Steven Vargas: votre merveilleuse réalisation hier en inscrivant le droit à l'avortement dans votre constitution. Je vous salue! Replying to "Barbara Barbara Friedland: 00:44:50 Friedland, P..." Decided to come and leave early. :) 00:44:50 Nina Martinez: The problem with lifetime thriver is that not all lifetime survivors are thriving or even alive. We have to stop pretending that equity has been reached. Nina, lifetime survivor. 00:45:14 Jim Pickett: Replying to "Barbara Friedland, P..." MWAH Thank you @Nina Martinez for that 00:45:26 victor reves: great point. FYI - info on lifetime survivors from 00:45:29 Annette Sohn: the Well Project: https://www.thewellproject.org/hiv-information/ lifetime-survivors-hiv Daniel D. Driffin, DrPH: My physician just 00:46:22 brought the statin results up in my appointment last week. I think we have to talk about since changing to an injectable ARV then adding a 'new pill' might not be for me. 00:47:00 Replying to "The problem with lif..." Larry Bryant: Yessssss 00:47:21 Jim Pickett: Replying to "The problem with lif..." great point 00:47:43 Jonathan Ayala: Replying to "The problem with lif..." Echoing - super great point. 00:48:13 Danielle Campbell: Replying to "My physician just br..." This!! Quelles dispositions sont 00:49:40 Lou Bly Bertine SEMI: prison pour les personnel du troisieme age sous traitement 00:50:37 Charles Chinguwo: Hi, I'm an AI assistant helping Charles innocent Chinguwo take notes for this meeting. Follow along the transcript here: https://otter.ai/u/ yf3nYIMLrbzPkVnFQ0klRk7LS7E?utm_source=va_chat_link_2

You'll also be able to see screenshots of key moments, add highlights,

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comments, or action items to anything being said, and get an automatic
summary after the meeting.
00:51:06
                Nina Martinez: Everyone keeps saying REPRIEVE trial,
and it's a trial that is 70% (presumably cis bc we don't recruit
trans) men. The cardiovascular risk is different in (cis and mavbe
trans if studied) women regardless of HIV because of the protective
effects of estrogen.
                Kennedy Mupeli: Allison and Judy what are your
00:51:16
thoughts on PLHIV using Vitamin supplements such as Vit D3 and K2. ?
                Nina Martinez: I have been living with HIV for 40
vears, am age 40, have gotten the statin push from ID docs, but I have
a zero calcium score and 10-year ASCVD risk of 0.5%. My cardiologist
says I don't need a statin.
All this to say individuals comprise studies, but we have to be
cautious of the ecologic fallacy.
00:53:55
                ANDREW TAN:
                                What actions shld we be lobbying for
now, considering that as ppl retire & move out of cities, like
establishing services & support systems in rural healthcare
facilities?
                Jim Pickett:
                                I definitely don't want to take a shot
00:56:35
every month - I don't need to see my doc 12 times a year!
                                6 mos sounds better to me
00:56:47
                Jim Pickett:
                                Replying to "I definitely don't w..."
00:57:18
                Nina Martinez:
 Agreed. If I have to go more than 2x a year, I am passing.
                                Replying to "I definitely don't w..."
00:57:21
                victor reves:
I go 2x a year and still feel like I go to often. Lol
00:57:31
                Jim Pickett:
                                Replying to "I definitely don't w..."
YES - that part
                Jim Pickett:
00:57:56
                                Replying to "I definitely don't w..."
It is such a burden
                                Thanks for all the great comments and
00:58:03
                Jim Pickett:
questions in the chat. Please consider raising your hand as well to
join in on camera ;)
00:58:05
                Jeff Berry:
                                Injectables are not for everyone, so
it's great to see the once weekly oral being developed, and there are
other orals in development. We need to continue to advocate for a
variety of delivery methods and formulations for treatment and
prevention.
00:58:38
                Daniel D. Driffin, DrPH:
                                                Replying to
"Injectables are not ..."
I'm on a weekly vitamin d pill and it is so hit and miss.
                               It would be nice if you're able to go
00:58:40
                victor reyes:
to a local CVS to get the shot administered.
                                Replying to "Injectables are not ..."
00:58:40
                JD Davids:
So true!
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00:59:10
                Jim Pickett:
                                I desperately want to have better
sleep!!
00:59:32
                Jeff Berry:
                                Replying to "Injectables are not ..."
@Daniel D. Driffin, DrPH 🤎
00:59:47
                Darren Lauscher:
                                        Replying to "I definitely
don't w..."
It might not be your doctor, more likely a nurse or even a pharmacist.
The reality is our doctors are hard to see and increasing our visit
rate will overwhelm them. Lots of administrative challenges to work
through.
00:59:52
                JD Davids:
                                Many more people have sleep
irregularities now due to Long COVID – it is a common symptom
including intense insomnia that doesn't respond to traditional sleep
hvaiene
01:00:20
                Nina Martinez: Insomnia in HIV was new news to me,
but then again I am unexpectedly early perimenopausal, and insomnia is
part of that blessing in aging as a lifetime survivor.
                JD Davids:
                                People with HIV who have had sleep
changes any time over last 4 years might want to consider that it's
from COVID and look into Long COVID peer and clinical support
                Jim Pickett:
                               Replying to "I definitely don't w..."
01:00:41
Well, I don't want to go to the clinic to see anyone 12 times a year!
NO thank you
01:00:54
                Daniel D. Driffin, DrPH:
                                                Replying to "I
definitely don't w..."
I'm on bimonthly. I don't see my physician during injections. I still
see him three times a year though and we communicate through our web
portal if I need anything.
01:01:30
                JD Davids:
                               And trans people who do not ID as men
or women
                Jim Pickett: the less I can engage with the health
01:01:33
care system the better
                Nina Martinez: Replying to "People with HIV who ..."
01:01:53
 Mine is definitely loss of estrogen and solitary kidney that is
working for two.
01:02:14
                Barbara Jungwirth:
                                        On the implementation front:
any thoughts about adherence to a once-weekly pill? For many people,
it may be easier to incorporate medications into a daily routine,
rather than remembering to take the pill once a week.
                Krishen Samuel: Replying to "People with HIV who ..."
01:02:20
Thanks for mentioning this JD!
                                Replying to "People with HIV who ..."
01:02:25
                JD Davids:
@Nina Martinez has anything helped?
                                Raise your hand to join the convo with
01:02:59
                Jim Pickett:
your beautiful voice and face
                Daniel D. Driffin, DrPH:
                                                Sleep is really
01:04:13
```

important. I think since COVID I've had the oddest sleep schedule. Mindfulness activities have helped but that is a subscription based service. I wonder if insurance (even Ryan White being mindful of US populations) would or should pay for it. Nina Martinez: Replying to "People with HIV who ..." 01:06:00 I need to ask about an estrogen patch (some kind of add back therapy) and maybe cut off fluids near bedtime. 01:06:35 JD Davids: I can't unmute but can anyone speak to yesterday's data about Covid and long COVID in PLHIV? Jeff Berry: Replying to "Sleep is really impo..." 01:07:12 Great point, Daniel. I use a subscription based service to reduce alcohol consumption which also includes a mindfulness component. Alcohol disrupts the sleep cycle big time. Nina Martinez: Replying to "Sleep is really impo..." 01:07:57 That's why Margarita Breakfast Club needs to come back (we already up) 🧀 Krishen Samuel: Shared and informed decision making is 01:08:03 so crucial. I'm under 40, and have been living with HIV for 15 years. I don't 'need' a statin yet, but have chatted to my provider about it. I don't feel ready to start taking it right now. However, REPRIEVE has certainly added a sense of urgency to start taking statins (which in itself can be anxiety inducing). 01:09:01 Steven Vargas: @Barbara Jungwirth, I anticipate a weekly dose would be rolled into weekly habits or rituals, like watching cartoons on Saturday mornings, or going to church on a Sunday. The day the weekly activity takes place becomes the day to take a pill. 01:09:15 Jim Pickett: I am on board for a weekly pill gimme gimme gimme 01:09:58 Jim Pickett: even where injectables are "available" there is a huge question about ACCESS 01:10:13 Krishen Samuel: And equitable access specifically... Kennedy Mupeli: We have no global consensus and 01:10:43 guidelines on the management of HIV and aging. Our healthcare system and policies in Africa are not providing for HIV and aging support programs. What can we do as aging activists to push this agenda into global agenda? 01:10:46 Danielle Campbell: Backwards! 01:10:58 Steven Vargas: @Jim Pickett, same here. Injections means more visits, so it's a no for me...plus I don't like shots. Danielle Campbell: Yes @Judith Currier 01:11:24 Jacque Wambui: Wow interesting note on development! 01:11:40 01:11:58 Daniel D. Driffin, DrPH: Toolbox of Treatment and Prevention 01:12:23 Lobna Gaayeb: See here the aidsmap article about CARES study of CAB+RPV in LMICs: https://www.aidsmap.com/news/ mar-2024/injectable-treatment-just-effective-standard-hiv-combination-

africa

01:12:24 Nina Martinez: Replying to "Shared and informed ..."

If folks painted a brush for everyone based on studies we'd be on injectables, Wellbutrin, zoledronic acid, and statins. And that's blatantly going to be an access problem.

01:13:05 Jacque Wambui: Replying to "See here the aidsmap..."

4

01:13:22 Daniel D. Driffin, DrPH: Replying to "Shared and informed ..."

My provider also highlights diet and exercise is still always important in these conversations.

01:13:27 Lobna Gaayeb: Did you know about this database for long-acting therapeutics? https://lapal.medicinespatentpool.org/01:13:28 Krishen Samuel: Replying to "Shared and informed ..."

Indeed, this is an important point. But sometimes, there's a feeling that in order to thrive and have a good quality of life, we NEED to be on all those.

01:13:36 Karine Dube: We will also need more therapeutic options for people with both HIV and HBV. Wondering if Judy could explain briefly.

01:14:01 Nina Martinez: Replying to "Shared and informed ..."

I think ableism drives a lot of this urgency, including diet and exercise.

01:14:17 Jeff Berry: Jim is there an update on the statement that was going to be made at the conference about people who walked out during the Martin Delaney presentation?

01:14:18 Lobna Gaayeb: The landscape tab is very interesting as it displays clinical trials timelines for some medicines (such as CAB and LEN) and the national filings of the drugs

01:14:21 Krishen Samuel: Replying to "Shared and informed ..."

Thanks for raising that Nina!

01:14:35 Larry Bryant: Replying to "Shared and informed ..."

There already is an access 'problem' correct? Access to healthy treatment options (even access to the unhealthy treatment options), access to information, access to the experience and expertise that can provide the correct information,

01:14:41 victor reyes: Is it mandatory to have to get the injectable at the clinic? I think the idea of going to a hospital monthly sounds like a lot. If it were able to get it sent to a local pharmacy or access it would be ideal.

01:15:27 Nina Martinez: Replying to "Shared and informed ..."

Right. If the correct thing to do was the easy thing to do, we'd be doing all that.

01:15:36 Mitchell Warren: Such rich conversation — thank

all three of you! I really appreciate the importance both Judy and Allison are making of planning R&D AND Delivery in parallel and not sequentially This is true whether for treatment or prevention, and really is the difference between developing biomedical OPTIONS and delivering feasible CHOICES (which is where it is all about the people, systems, programs, etc. end not just the product).

01:15:49 Krishen Samuel: Replying to "Shared and informed ..."

Most certainly. I think access to information is a big one. I often tell my doctor about recent study results...

01:15:53 Allison Agwu: Replying to "Is it mandatory to h..."

These things are being worked out, very good point 01:16:22 victor reyes: Great points Jim

01:17:29 Jim Pickett: Replying to "Jim is there an upda..."

A statement will come out today Jeff!

01:17:47 Jeff Berry: Replying to "Jim is there an upda..."

Thanks!

01:18:04 Jim Pickett: Replying to "Jim is there an upda..."

From the Community Educator Scholars and community advocates — stay tuned ;)

01:19:15 Julie Patterson: Replying to "Jim is there an upda..."

(

01:19:40 Aisuluu Bolotbaeva: Replying to "Jim is there an upda..."

@Jim Pickett♥

01:20:06 victor reyes: Why aren't there more DOT programs or facilities? I think having a one-stop shop/facility for people receiving all kinds of care needs a place to get medication and bond with others. Taking medication is so isolating, and from my experience, going to DOT with friends was a big step in my being adherent.

01:20:08 Jim Pickett: Replying to "Is it mandatory to h..."

I have pharmacy within 5 minutes walk of my home — but no way would I want to go there for shots in an ongoing way — always a long line, always under staffed — also a no thank y ou

01:21:13 Jim Pickett: Replying to "Why aren't there mor..."

Nice idea

01:22:43 Barbara Friedland: AGREE!!! there is so little on women (I thought I was just being hypersensitive...)

01:23:11 Jeff Taylor: ^^^^^^^\

01:23:50 Nina Martinez: Table 1 tells a story. So does the author list.

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01:24:46
                Udom Likhitwonnawut:
                                        Great points, Aisuluu. Access
to affordable is always a big problem for middle income countries - we
are not rick enough to get trade name medicines and not poor enough to
get benefit for voluntary licensing.
01:24:56
                Danielle Campbell:
                                        Replying to "AGREE!!!
is s..."
a far too commonly accepted issue within research.
01:25:00
                Jim Pickett: "when it comes to the animals, come
on"
01:25:07
                Nina Martinez: All trans folks are historically
excluded from studies.
01:25:14
                Jeff Taylor:
                              In terms of representative
demographics, we also need ensure we have sufficient representation of
people over 65 who experience the most cormobidites. Most
participants tend to be 40-60, which doesn't serve us well as our HIV
population continues to age
01:25:30
                Jeff Taylor:
                               ALL gender-nonconforming folks
01:25:41
                Barbara Friedland:
                                        Transmen are woefully
underrepresented....
                Jim Pickett:
01:25:44
                                combining trans women and gay men is
SUCH A MESS .... and thank you for uplifting TRANSMEN
                Nina Martinez: Get trans and NGC folks on your study
01:25:56
team and they will figure that out for you.
                Shekinah Rose: Yes we need to increase trans
01:26:09
inclusivity
01:26:09
                Jim Pickett:
                                Replying to "Get trans and NGC fo..."
BING0
                               There needs to be an app or portal
01:26:38
                victor reyes:
that can be accessible to HIV+ folks to sign up for trials, research,
etc, in real-time and give more opportunities for us to become more
proactive in research.
                                                "Hardly reached!" That
01:26:39
                Daniel D. Driffin, DrPH:
is it!
01:26:43
                                trans men are often not included in
                Jim Pickett:
prevention studies - cuz its just "too complicated"
01:26:49
                Shekinah Rose: Medical distrust is a barrier!
01:27:26
                Nina Martinez: The doxyPEP trial in Seattle/SF is
case in point how author list (cis women) determines who is in Table 1
(8% trans women)
01:27:38
                JD Davids:
                                Check out the No Data No More
manifesto on trans inclusion in hiv prevention research from AVAC!
                Krishen Samuel: The enrollment vs. exclusion part is
really important when it comes to trans and non-binary communities.
Also, researchers using the words 'men' and 'women' when some
participants identify as non-binary is a form of misgendering.
                Mitchell Warren:
01:27:44
                                       Thank you @Allison Agwu — from
"hard to reach" to "hardly reached", and the burden to reach needs to
be on the systems and programs, and not on the individuals not
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reached.
                                IAS may be a better venue than CROI
01:27:53
                Jeff Tavlor:
for addressing programmatic issues around aging
                Mitchell Warren:
                                        Replying to "Check out the No
Dat..."
Thanks, JD! The manifesto is at https://avac.org/resource/report/no-
data-no-more-manifesto-to-align-hiv-prevention-research-with-trans-
and-gender-diverse-realities/
01:28:36
                                Replying to "Thank you @Allison A..."
                Larry Bryant:
11111
                JD Davids:
                                Replying to "trans men are often ..."
01:28:46
lol I'm complicated
                Jeff Berry:
                                Replying to "IAS may be a better ..."
01:29:07
Yes, there will be a lot of activities at IAS around HIV and aging
01:29:19
                Jim Pickett:
                                This has been such an awesome session
- we will be closing out in a few minutes - thank you for such a rich
discusson
01:29:26
                Jeff Taylor:
                                Replying to "trans men are often ..."
Trans men are no more complicated than trans women—just
underepresented
01:29:31
                Larry Bryant:
                                Replying to "trans men are often ..."
Ummmm...
01:29:36
                Jim Pickett:
                                Replying to "trans men are often ..."
JD - you are mos def complicated MWAHHHHHHHHHHHHHHHHH
01:29:52
                Reena Rajasuriar:
                                        Thanks Annette. This is the
link to the JIAS Supplement on HIV and Aging
https://onlinelibrary.wiley.com/toc/17582652/2022/25/S4
                Krishen Samuel: Replying to "Check out the No Dat..."
01:30:02
Here's my aidsmap coverage of that great manifesto: https://
www.aidsmap.com/news/jul-2021/how-can-hiv-research-better-align-
realities-transgender-and-gender-diverse-people
                                Replying to "trans men are often ..."
01:30:10
                Jim Pickett:
Jeff - I will share some "too complicated" stories from the prevention
world
01:30:13
                Jeff Taylor:
                                We also saw hundreds of researchers
walk out on that session, sadly
01:30:14
                Nina Martinez: Replying to "The doxyPEP trial in..."
 You need a study team with cultural competency, and PIs make these
hiring decisions. Same input, same output.
                                Replying to "trans men are often ..."
01:30:31
                JD Davids:
Just ask my partners hahahaha
                Darren Lauscher:
                                        Thanks to the presenters and
01:30:56
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to my peeps from around the world most amazing conversations and
thoughts.
01:31:11
                Jeff Taylor:
                                Replying to "trans men are often ..."
@Jim Pickett 🙏
01:31:25
                Shekinah Rose:
                                It's a BIG problem
01:31:45
                                Nothing about us without us
                Shekinah Rose:
01:32:05
                victor reyes:
                                Thank you everyone! Thank you,
Annette, Allison, Judith, and Jim!
                                Replying to "Thank you @Allison A..."
01:32:11
                Nina Martinez:
 Say the truth: they find them hard to connect with
01:32:32
                Krishen Samuel: Thanks for a wonderful, informative
session.
                Olivia G Ford (she/they) - The Well Project:
01:32:48
Replying to "Thank you @Allison A..."
縱
01:32:54
                JD Davids:
                                So much vital truth in the
presentation, discussion and chat! Thank you!!
01:32:55
                Nina Martinez: Haha tired canary 😅
01:33:01
                Steven Vargas:
                                Another great session. Thank you!
                                Thanks so much Allison & Judy!
01:33:07
                Jeff Taylor:
                                Either 'not thought about' or 'don't
01:33:07
                Larry Bryant:
want to think about (them)'...
                Nicoletta Policek:
01:33:13
                                        Thank you a very informative
session
01:33:16
                Mitchell Warren:
                                        Why and why not! And who and
who not!
01:33:33
                Arda Karapınar: I'll see those of you who are here in
the conference room and the others on CBC tomorrow morning.
I wish everyone a wonderful day♥↓↓
01:33:36
                Jeff Taylor:
01:33:44
                Udom Likhitwonnawut:
                                        Thank you to the presenter and
moderator. Great job!
01:33:49
                Jacque Wambui:
01:33:51
                Olivia G Ford (she/they) - The Well Project:
you all so much! Awesome conversation on screen and *chat*, crucial
framing for the whole conference, brilliant folks, all!
01:33:52
                Mitchell Warren:
                                        You need to get some sleep,
Jim!
01:33:59
                Rosie Mngqibisa:
                                        great session— thank you!
01:33:59
                Shekinah Rose: Thank you
01:34:01
                Julie Patterson:
                                        Have a great day, community
educator scholars! Go get them!!
01:34:02
                Apostolos Kalogiannis:
01:34:07
                Jeff Berry:
                                Thanks everyone, another great
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program!

01:34:10 Moses Supercharger: GREAT PRESENTATIONS SO

RESOURCEFUL THANK YOU

01:34:13 Higgin Joseph: This conversation has been really

insightful

01:34:19 Nina Martinez: Replying to "trans men are often ..."

Lol, JD! 😂

01:34:31 Dawn Averitt: Amazing trio! Thank you all!

01:34:36 Larry Bryant: Thank you Dr. Agwu and Dr. Currier! 01:34:37 mario cascio: Thanks to presenters and moderator,

great conversations

01:35:04 Aisuluu Bolotbaeva: Thank you dear Annette,

Allison and Judith!

01:35:16 Annette Sohn: Thanks for including this topic in the

CBCs!

01:35:19 Ronald Johnson: Thanks very much for a good session.