

Mark Masselli: This is Conversations on Health Care, I'm Mark Masselli.

Margaret Flinter: And I'm Margaret Flinter.

Mark Masselli: Well Margaret, we've ended the year on a pretty astounding note. Nearly 200 nations have finally signed onto an agreement to combat climate change.

Margaret Flinter: And the UN's Climate Change Conference in Paris yielded a historic agreement to contain CO2 emissions emerging nations such as India and China and as they are discovering in China with the devastating air quality issues that they are having there, greenhouse gas emissions are a real threat to human health.

Mark Masselli: And the World Health Organization is deemed climate change and global warming is the biggest threats to the human health in the 21st Century.

Margaret Flinter: And the World Health Organization's Director has urged the world's health care providers to become champions of efforts to limit the hazards to health that are wrought by CO2 emissions and the globe's warming temperatures.

Mark Masselli: Other health issues that had a devastating effect on global health, the AIDS epidemic which has caused the death of 23 million people around the world.

Margaret Flinter: And our guest today is on the front lines of seeking a cure for this deadly pandemic. Kevin Robert Frost is the CEO of amfAR, one of the first nonprofit organizations formed over 30 years ago to confront the AIDS epidemic by sponsoring research to find a cure.

Mark Masselli: Lori Robertson also stops by, the managing editor of FactCheck.org, is always on the hunt for misstatements spoken about health policies in the public domain but no matter what the topic, you can hear all of our shows by going to chcradio.com.

Margaret Flinter: And as always if you have comments, please email us at chcradio@chc1.com or find us on Facebook or Twitter because we love to hear from you. We will get to our interview with Kevin Robert Frost in just a moment.

Mark Masselli: But first here is our producer Marianne O'Hare with this week's headline news.

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Marianne O'Hare: I'm Marianne O'Hare with these Health Care Headlines. The good news is, there is a cure. The not so good news the cost the drug that successfully cures hepatitis C is starting to have an impact not only on the health of those suffering from the liver killing virus but it's also taking a toll on state Medicaid budgets. In 2014, 33 states spent a combined \$1 billion treating hep C patients with Sovaldi Gilead

Services hep C curing drug that runs on average \$84,000 to treat one patient that was spent in less than 3% of the Medicaid patients in need of the drug and those on Medicaid are told they have to wait until they are sicker.

Florida may not have expanded Medicaid but the state is taking up the subject of medical marijuana that would allow prescriptions for medical marijuana for patients suffering from a number of debilitating diseases. 23 states in the District of Columbia meanwhile allow marijuana use for those suffering from a range of ailments from HIV, glaucoma, cancer and epilepsy and melanoma is on the rise the FDA is considering a ban on minors using tanning beds in an effort to cut down on the rise of skin cancer in young people.

The CDC's Tom Frieden continues to urge Americans to get the flu shot this year warning that window is narrowing before flu season kicks into high gear. Meanwhile Google has made inroads in the business of tracking the flu epidemic which is off to a slow start thanks to the unusually warm weather, Google's Flu Trends have provided public health officials with real time tracking analytics on flu outbreaks throughout the country. Now it's turning its sites on sexually transmitted diseases which are on the rise in this country and elsewhere. Public health researchers say tracking for prevalence of searches for things like painful urination could target their efforts to do more outreach in areas with higher queries on the Google search engine. I am Marianne O'Hare with these Health Care Headlines.

(Music)

Mark Masselli: We are speaking today with Kevin Robert Frost, Chief Executive Officer of amfAR, the Foundation for AIDS Research, a 30-year-old organization dedicated to advancing the science that will end the HIV AIDS pandemic. Mr. Frost has served on President Obama's Advisory Committee on HIV AIDS and as Vice President of Global Initiatives, he also served on the Advisory Committee for the 14th and 16th Annual AIDS Conference in Barcelona and Toronto and has worked as an inpatient coordinator for the AIDS Program at New York City's Bellevue Hospital. Mr. Frost has advised the FDA on breakthrough age drug development. Kevin welcome to Conversations on Health Care

Kevin Robert Frost: Thanks for having me.

Mark Masselli: So amfAR was formed three decades ago as one of the first not-for-profit research organizations dedicated to seeking a cure for AIDS and when you joined in 1994 an HIV or AIDS diagnosis was synonymous to a death sentence in most cases, could you talk to our listeners about the early days of amfAR and how your community of experts help turn the tide in treating the AIDS epidemic?

Kevin Robert Frost: Before I came to amfAR, immediately before I came to amfAR, I was working at NYU Bellevue Hospital here in New York City and I was working on a research protocol for an infection that a lot of people with AIDS got which was called CMV and it was an infection in the eye that would lead to blindness, and they were mostly men in those days when they would come to our clinic to be enrolled in these research protocols their average life expectancy was nine months.

We are living in a whole new world today in which people with an HIV diagnosis if they are fortunate enough to live in a country where they have access to treatment and they have access to a doctor and health care can expect to live a normal healthy life well into their 70s which is not to say that it's still not complicated you are dealing with a chronic illness, but we have just made enormous progress as a result of having changed the research paradigm in this country and having changed the drug approval process which led us to the point where we were able to make enormous strides. A 30-year-old epidemic sounds like a long time but the amount of progress that we have made in fighting this disease and understanding this disease has been nothing short of astonishing.

Margaret Flinter: When you look at the list of achievements that have been accrued by amfAR, your early work led to the development of protease inhibitors and maybe share with us what was remarkable about those early days of AIDS research given how little we actually knew and how did some of those early discoveries really shaped the treatment protocols that are so commonplace to that?

Kevin Robert Frost: 25 and 30 years ago there wasn't a lot of money being spent in research and in fact amfAR was one of the first organizations to understand at least on the nonprofit side that it was only going to be investments in research that would bring us the kind of answers that could make a difference in fighting the epidemic. The NIH and pharmaceutical companies were not investing huge sums, and so we were able to leverage even small amounts of money to achieve important breakthroughs.

The philosophical way in which amfAR has approached its work is very different from the way the NIH and pharmaceutical companies and those with large amounts of money sort of approach their work. We have from the very beginnings of this organization viewed ourselves as venture capitalists in research if you will. We've never had an endowment here because we have always believed that our job as an organization was to put ourselves out of business.

So we have made investments with every dollar that we have been able to raise but we have done it in the highest risk areas knowing that a lot of those investments would fail but the ones that would payoff we hope at least would have an outsize impact, and I think that's been true in the area of protease as you have mentioned but also in the area

of CCR5 as you have mentioned mother-to-child transmission and other ways that we have had significant impact it's because we have taken greater risks to get there.

Mark Masselli: Here in America AIDS was really very much associated with diseases of the gay population or IV drug users but in the Third World where there is a much wider pandemic amfAR has been pioneering research on mother-to-infant infection how close are we to get into zero mother-child infections?

Kevin Robert Frost: Globally, this is an epidemic between men and women, and as a result of that it is an epidemic of transfer from mothers to their newborns. We have essentially all but eliminated infections from mother to newborns here in the west but we still have a very long way to go in terms of eliminating those infections in the developing world. And the big part of the problem is just simply access to health care, particularly, prenatal care because we know putting people on treatment for HIV disease will prevent transmission from mothers to their newborn. There are nearly 39 million people living with HIV globally and roughly 15 million of them are on treatment meaning less than half, 40%, and if you roughly estimate that half of those are women you see what kind of a challenge we face and very often what they have to do with are all of the tangential issues that surround access to health care and aren't necessarily specific to our understanding of how to prevent transmission from mothers to their newborns.

Margaret Flinter: amfAR played an early role in promoting some of the really important government policies both domestically and globally. There was research going on but access to trials was actually quite limited. So could you talk with us a little bit about the government policies that were spearheaded by amfAR such as the HOPE Act and the Ryan White CARE Act

Kevin Robert Frost: Well what the early HOPE Act did and eventually what Ryan White did is that it provided a framework for the states to take federal money and use that money in service to providing care for people with HIV. And in many states, particularly in the south, the only money that was spent in many of those states on HIV AIDS was money that came from the federal government a big part of that in my view was related to sort of the stigma and the populations that were affected here, they tended to be drug users, they tended to be gay men, they tended to be all these populations that a lot of states didn't want to look at or deal with.

What we were able to do here early on in the epidemic was to understand very clearly the political dimensions of HIV disease. And it was really one of the first diseases I think that we really had a very big political dimension to it and part of the reason for that was the lack of a political attention that the disease received. President Reagan did not publicly speak about HIV until 40,000 people in this country had already died from it. And you contrast that with something like legionnaire's disease and how much front

page newspaper attention that disease was receiving when only a handful of people were afflicted by it, the population affected were different and reviewed differently by society and certainly by politicians, and I think by understanding those political dimensions we were able to advocate for policies that ultimately made access to health care, access to treatment and even by extension access to research more available to the people who needed it most.

Mark Masselli: We are speaking today with Kevin Robert Frost, Chief Executive Officer of amfAR, the Foundation for AIDS Research, a 30-year organization dedicated to advancing the science that will end the HIV AIDS pandemic. Now I want to talk about that intersection of the political and the regulatory we had the opportunity of having Commissioner Hamburg from the FDA on the show recently and I am going to have you share with our listeners how you worked your collaboration with drug makers as well as with the FDA what the experience has been and what's the state of that relationship today.

Kevin Robert Frost: If you roll back the clock 30 years to the early years of the AIDS epidemic what you found was an agency that was entrenched in its views and those were largely dinosaur-ic about how the drug development process had to happen and what it wasn't prepared to do was respond quickly to an emerging epidemic the way HIV was. So activists came together and working with organizations like ours many others were able to effectively change the paradigm of how drug approvals were done at the FDA and created systems that had never been created before like parallel access to experimental medicines such that even before a drug would get approved community access could be made available to those who didn't qualify for clinical trials.

When we first began almost all drug trials in this country were done in academic settings. There is no H drug that has probably come onto the market in the last decade that hasn't had the vast majority of its broad access research done in doctor's office in the very communities where it's needed most and that has not only sped up the research process itself but it's provided greater access to people for experimental medicines the ones who absolutely need it most.

Margaret Flinter: If you had told me a few decades ago that we would now have HIV drug protocols that allow for a normal lifespan in most cases I would have been stretched to believe that but what's really remarkable is that global health officials target 2030 as their year for a cure. Tell us and our listeners about some of the functional cure stories that have garnered recent attention the so-called Berlin Patient or the Visconti Cohort and what kind of promise do these stories hold for the broader population?

Kevin Robert Frost: It all begins in my view at least with the Berlin Patient because this was really and truly a pivotal moment in the history of AIDS research. The Berlin Patient is a story of a young man who was living with HIV for many years who was diagnosed with cancer and needed to undergo a bone marrow transplant as part of his treatment. His doctor used a very experimental protocol in which he found a donor who happened to have a mutation in a protein on the surface of CD4 cells called CCR5.

And we know that CCR5 is the entry way for HIV. This person underwent this bone marrow transplant and ultimately he adapted the immune system of the donor and became resistant to HIV infection, and so ultimately he is the only person whom there is broad scientific consensus has been cured of his HIV disease. For the very first time, we had at least proof that someone could be cured even if we couldn't replicate it and we have not been able to replicate it, it showed that someone could be cured of this disease.

And what we then moved from was an era of discovery research because we had spent 25 years in the epidemic trying to understand all of the elements. We moved out of that era and into an era of technological challenge through the Berlin Patient we now understood what the challenges were to curing people and over the course of the last seven or eight years there has been this tectonic shift in the thinking of scientists around what it would take to cure people.

But in addition to that you have these other stories that you mentioned like the Visconti Cohort in Europe which is a group of people who have been living for a very long time with HIV but have essentially self-intact immune systems, immune systems that are effectively controlling the infection and what that has done is provided a different kind of paradigm which is more akin to sort of our understanding of how to approach cancer which is to create a remission.

And so we largely moved away from the use of the term functional cure because what we are actually trying to do is create an environment in people where in their own immune systems whether stimulated through a vaccine or stimulated through certain treatments could effectively control HIV infection. The HIV isn't causing any disease, it's not infectious to other people and it's controlled without the use of ongoing treatments or drugs. And so that would be a state of remission I think that will really probably be the next step in our journey towards ultimately developing a cure which will rid [ph] the body of HIV.

Mark Masselli: Well Kevin we are working to contain the spread of virus through targeted prevention measures and the western world has done a pretty good job for the most part but there are pockets of concern some 50,000 new infections occur each year in this country while the many HIV positive people are getting the antiretroviral drugs

millions more have yet to gain access to these life saving treatments and new drugs like Truvada the so-called PrEP Approach are showing great promises in preventing transmission can you tell our listeners about prevention methods and what can be done to improve our prevention efforts?

Kevin Robert Frost: Certainly any conversation around prevention begins with condoms because they have been enormously effective in our 30-year battle with this disease. You also have things like syringe exchange which had driven down the rates of new infections at least here in the state of New York they are reporting zero new infections in injecting drug users largely because of a very long campaign to provide clean syringes for those who are injecting drugs. Circumcision has been proven to reduce the rate of acquisition and so you have circumcision programs throughout Africa which are highly effective you have mother-to-child transmission programs which have reduced the rate of transmission from mothers to their newborns. You mentioned PrEP which is a single daily pill that can prevent the acquisition of HIV then that's being used a great deal particularly here in the west in gay communities and then you have something that came out of a study just a couple of years ago which was also I think a seminal moment in our history which is referred to as the HPTN study 052.

What the 052 study showed was that when you put people on treatment and they are effectively treated meaning their viral load levels are driven down so low that they are undetectable, those people have a 0% chance of transmitting the virus to their partners. This is virtually zero chance of transmitting it. So if you add up all of these interventions we actually have the tools in our grasp today to completely and radically change the trajectory of the epidemic worldwide. We could drive down 50,000 new infections to nearly zero in this country.

The reason we haven't been able to do that is because we don't have the political will and the financial investments to back up the scientific achievements, and so until we are prepared to make those investments we are never going to get to the point where we can end the epidemic through those methodologies alone that's why we continue to invest in peer research it's why we need a vaccine if we really want to end the pandemic worldwide.

Mark Masselli: We have been speaking today with Kevin Robert Frost CEO of amfAR, The Foundation for AIDS Research, a 30 year organization dedicated to advancing the science that will end the HIV AIDS pandemic, you can learn more about their work by going to amfar.org or you can follow them on Twitter @amfAR. Kevin, thank you so much for the work that you are doing and for joining us today in Conversations on Health Care

Kevin Robert Frost: Thank you for having me.

(Music)

Mark Masselli: At Conversations on Health Care, we want our audience to be truly in the know when it comes to the facts about health care reform and policy. Lori Robertson is an award-winning journalist and managing editor of FactCheck.org, a nonpartisan, nonprofit consumer advocate for voters that aim to reduce the level of deception in US politics. Lori what have you got for us this week?

Lori Robertson: Hillary Clinton said at the democratic presidential debate in November that nearly 3,000 people had been killed by guns including 200 children since the democrats had last debated about a month before. Some of our readers asked us if that was correct. Comprehensive data on that specific timeframe isn't available instead Clinton extrapolated the numbers based on figures on gun deaths from past years. In 2013, there were 33,636 gun deaths according to the Centers for Disease Control and Prevention that averages to about 2,800 gun deaths or nearly 3,000 as Clinton said, each month of the year. These are the most recent numbers from the CDC. They include suicide which made up 63% of gun deaths that year, homicides 33% of gun deaths and unintentional discharges, legal interventions or war and undetermined causes. As for firearm deaths of children the Clinton campaign relied on figures from 2010. The 2013 CDC figures for children 19 and younger back her up those gun deaths average 205 per month but if we look only at those age 17 and under the average killed by month was 105. We won't know the number of gun deaths for 2015 for another year or so and even then we won't be able to look at the number for a specific time period as Clinton cited.

A group called the Gun Violence Archive seeks to provide near real-time tracking of gun incidents through media, government and other sources. For 2015 it counts 11,633 gun deaths through November 18 but that number doesn't yet include suicides which the group says are not reported the same way as other incidents. The group's executive director told us Clinton's 3,000 figure would likely be right at least based on a monthly average for the year once suicides are included, and that's my fact check for this week. I am Lori Robertson Managing Editor of FactCheck.org.

Margaret Flinter: FactCheck.org is committed to factual accuracy from the country's major political players and is a project of the Annenberg Public Policy Center at the University of Pennsylvania. If you have a fact, that you would like checked, email us at www.chcradio.com. We will have FactCheck.org's Lori Robertson check it out for you here on Conversations on Health Care.

(Music)

Margaret Flinter: Each week Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. Right now there are about 3.5

million people living in refugee camps around the world whether displaced by wars or natural disasters the plight of these people is often the same living in squalid conditions intensities that provide little protection from harsh elements. The IKEA Foundation has taken the parent company's widely successful Do It Yourself approach to home furnishings and applied it to the problem of inadequate housing for displaced refugees. They have created a Do It Yourself dwelling that can be shipped and assembled anywhere.

Jonathan Spampinato: So first and foremost there is the very well-known flat pack approach that IKEA has pioneered, secondly the materials in the product itself, so it's a shelter it's not a tent.

Margaret Flinter: Jonathan Spampinato is the Head of Communications and Strategic Planning at the IKEA Foundation. They are working closely with United Nations organizations working on the ground.

Jonathan Spampinato: We extended that to also include funding for an innovation unit within the UNHCR so they could think more long term so providing that funding allowed them to start the refugee housing shelter looking at how to design a better shelter.

Margaret Flinter: And these IKEA structures have some unique properties that can make the experience more bearable.

Jonathan Spampinato: The walls and the roofs are made out of a new fancy version of basically a plastic material that is much more durable but very, very light weight and still it's insulated.

Margaret Flinter: The IKEA Foundation currently has prototypes and true to IKEA the price point is going to come in under a \$1,000 per structure, a deliverable, affordable, Do It Yourself dwelling that can provide some sense of dignity, privacy and protection for families who are struggling as refugees, now that's a bright idea.

(Music)

Margaret Flinter: This is Conversations on Health Care, I am Margaret Flinter.

Mark Masselli: And I am Mark Masselli, peace and health.

Conversations on Health Care broadcast from the campus of WESU at Wesleyan University, streaming live at www.wesufm.org and brought to you by the Community Health Center.