

About Health TV with Jeanne Blake
Getting tested
www.abouthhealth.com

JEANNE BLAKE: Welcome to *About Health TV*. I'm Jeanne Blake. Take control of your health. Get tested for HIV. That's the message of the new Massachusetts Department of Public Health campaign. On this edition of *About Health TV* we'll talk about the HIV epidemic among people of color, and we'll learn of two new efforts here in Massachusetts to encourage people to get tested for HIV to learn their options. We're joined for this discussion by Dr. Jeanne McGuire, who is an assistant commissioner of public health at the Massachusetts Department of Public Health. Dr. McGuire runs the HIV bill, and she's joined by John Ruis, who is the consumer office coordinator and is a man living with HIV. Thanks for coming in to both of you. Dr. McGuire, historically it's been a challenge to reach people of color with prevention messages. Why?

DR. MCGUIRE: Well, I think that we have to recognize that this is an incredibly stigmatized disease, and in fact one of the important motivators for us undertaking this campaign is that we've been struggling how to figure out how to deal with stigma. I think communities of color have experienced stigma in many ways beyond this particular disease. All you have to do is look at the disparities in health care access that exist across the board. So I would say that this additional stigma is a hard one to embrace when you're already struggling with a lot of access problems and a lot of prejudice.

JEANNE BLAKE: That makes a lot of sense. In designing the campaign, then, how did you deal with that?

DR. MCGUIRE: Well, we're very fortunate in this state. We continue 20 years in the epidemic to be the only state that actually has a consumer office – John is the coordinator of it – and we looked in the literature and we realized there wasn't any simple answer to how do you address stigma, and we brought together people living with the disease through John's office to advise us.

JEANNE BLAKE: And, John, what did you tell Dr. McGuire to help break down the barrier?

JOHN: Well, members of the statewide consumer advisory board, which is a group of consumers from across the state who advise the bureau of policy and program development, they came up with the idea of developing a brochure that was consumer driven, that was a message to

people at high risk of infection to get tested ... a message from people who had already been through the testing process and survived it.

JEANNE BLAKE: Okay, that seems very basic, because of the peer approach of the epidemic the last 20 years, so it does seem a bit logical.

JOHN: Absolutely. I think that when people with HIV in this campaign – there are photographs of people living with HIV who identify as HIV positive – I think that whenever people with HIV come forward and put a face on the epidemic, it really demystifies it for the community and humanizes it and helps to reduce the stigma associated with it.

JEANNE BLAKE: You were tested in 1986?

JOHN: Yes.

JEANNE BLAKE: What inspired you to get tested so early on?

JOHN: Well, the test had just been made widely available to the public, and I knew a school teacher of mine who had AIDS, and he encouraged me to go get tested. But I struggled with the decision to go get tested because of the implications of a positive test result, the fear of being stigmatized, and the fear of also being outted regarding my sexual orientation. The disease back then was strictly associated with gay men, and so I had this incredible fear of getting tested, but I finally did. But even after getting tested, it took me a year to go get the results.

JEANNE BLAKE: But I think it's interesting that without that personal – it's very similar to sort of the philosophy around putting the pictures on the brochures, which we'll show a picture of -- that this man represented a very personal connection for you and it did get you to get tested. But you didn't get your results for a year because of the fear that you described so well.

JOHN: Fear. Deep down inside I knew that I was positive, and I wasn't ready to deal with that information. At the time, besides having to deal with the stigma associated with the disease, there wasn't any treatment. So what was the point of knowing that one was positive if one couldn't be treated?

JEANNE BLAKE: So what do you mean you knew deep down inside that you were positive?

JOHN: Well, you know, I had read reports about what were the risk factors associated with contracting this disease and I knew that I had been involved in some of those risk factors as a gay man. And so I felt that, you know, how could I have escaped?

JEANNE BLAKE: So looking back, you went a year later and got your results. Why did you finally go get your results?

JOHN: Well, I decided that I wanted to know once and for all because I was living with this uncertainty for a whole year and I just had to know. I was compelled. I was telling Jeanne before the show that I went during my coffee break. I was working at the local welfare office in Springfield, and the Department of Public Health was across the street, and I decided to go. I don't know what compelled me at that moment to go across the street and get my results. And sure enough, it was a positive test result. I just went into shock and isolation after that.

JEANNE BLAKE: For how long?

JOHN: For a long period of time, I would say years.

JEANNE BLAKE: Really?

JOHN: I would say it was a secret that my partner and I maintained for four or five years. I didn't feel safe disclosing that to my family or the community or work. And so we kept my secret until I got to know other people with HIV and learned about the circle of care, treatment, and non-medical treatment that was becoming available and then decided to avail myself of that.

JEANNE BLAKE: But you don't regret getting tested?

JOHN: Absolutely not.

JEANNE BLAKE: And finding out?

JOHN: Absolutely not. I think it's the best decision I ever made, because I believe that I'm alive today because I knew my status. I've been living with this disease now for 19 years.

JEANNE BLAKE: Which is amazing.

JOHN: I don't think that I would be alive today if I weren't in treatment.

JEANNE BLAKE: That's right. Because finding out – I mean, that's what the campaign is designed for, is to get people into treatment more, because you can stay healthy for a long time, but also so that you're taking fewer risks, I imagine, in exposing other people. Is that right?

DR. MCGUIRE: Well, I think that one of the things that's important about this is that it's not so much that the idea of putting a face on the epidemic is new. Thank God we figured out that that was important quite a while ago. That's what helped you get into treatment and helped other people think that there's somebody there to be of support and allowed us to create really the circle of caring you're talking about. But I think what was different was that even the Department of Public Health approached recommending testing with a great deal of ambivalence for a long time. And we've since embraced that, we're strongly recommending it, and suddenly we realize that there really was no voice that was stronger to recommend it than people who had benefited from knowing their status. So it seems to me that we took a long time to come around to something we should have realized was a very powerful response.

JEANNE: But the campaign – and I think you alluded to this – is more than a brochure or a plaque. Once you go through the door and you get tested, the services are there.

DR. MCGUIRE: The services are there, but the campaign is really about mobilization, and I think that when you look at the information coming out of Barcelona right now and the extent to which not just U.S. officials but worldwide officials are talking about complacency, we have to re-imagine how we mobilize people around it, and so the messages within the campaign that consumers are giving are incredible important. There's messages about responsibility, something we've been very hesitant to talk about. There's messages about not having to do it alone and there's messages, thank God, in this state that care and support are free. And we can continue to say at this point that there's no financial barrier to getting help if you have HIV in this state, and that's a tremendous opportunity.

JEANNE BLAKE: Do you think that that will continue to be? You're facing at the state level tremendous budget cuts, you've lost \$10 million of your \$50 million funding from last year, and will

some of those services disappear if the budgets are further cut?

DR. MCGUIRE: Well, certainly some of those services have already shrunk and in some cases disappeared from where they were located. Midyear, when the cuts occurred, we had to eliminate 48 contracts that we had and we had to reduce another 70. So that's a tremendous impact across the state, and what we've done – and John in the consumer office has been a big part of it, along with our partners in the communities – we've worked statewide with folks about how do we fill the gaps, how do we have some creativity? The city of Boston was an incredibly important partner in that. And so at the moment I think we've done a lot to fill some of those holes, but the safety net is frayed, and just at a time when we're trying to expand the number of people who know their status. The data that we put out is not dissimilar to what the national estimates are. We think one-third of people living with HIV in this state either don't know their status or don't care.

JEANNE BLAKE: But should I, as a person who's considering getting tested, if I were John in 1986 hearing you talk, I might say, well, the services aren't going to be there so I'm not going to get treated well?

DR. MCGUIRE: I feel totally confident right now with saying if you get tested we can take care of you, we can support you, and that we may have to find more creative ways to do it with somewhat less resources. But unlike most jurisdictions, certainly most of the world and many other parts of this country, we can say there's no financial barrier to care.

JEANNE BLAKE: Right, but Massachusetts has been a leader in the epidemic, and Boston has been – as you mentioned – been a terrific partner.

DR. MCGUIRE: The way I think, nationally, from all the traveling I've done, I think that Massachusetts is the place to be if you are living with HIV.

JEANNE BLAKE: Absolutely. Dr. McGuire, thank you for coming in to tell us a bit about the campaign. Good luck. We'll keep our fingers crossed that the budget won't be slashed more. And John, you stay with us, because in just one moment we're going to learn about another program. This one, a program of the Massachusetts AIDS Action Committee. And we'll be right back. ... We continue our discussion talking about the urgent need for people of color to get tested to learn their HIV status, and we continue our discussion, of course, with John Ruis, who is with us from the Department of Public Health. We're joined now by Robin Fuller, who is the coordinator of the AIDS Action Committee

of Massachusetts. Thanks, Robin, for coming in to join John and me to talk about this important issue. You have a new campaign that you're kicking off and it is called the ...

ROBIN: Getting People into Care campaign.

JEANNE BLAKE: What is that? What does it consist of?

ROBIN: Basically it's a billboard campaign that's going to be displayed throughout the Dorchester, Roxbury, Mattapan area encouraging people, now that you've been tested, to immediately follow up with care. And the churches in the area have stepped out to show their support and their goal of responsibility in helping people get into care, not only medically but non-medical services that are being provided by the churches and other AIDS service agencies in the area.

JEANNE BLAKE: John, it's got to be really heartening for you as a man who's been living with HIV since 1986 to hear Robin describe this campaign as the first billboard campaign that's being backed by the churches, because as a reporter in Boston, I reported many times about the desire to bring the black community through the church and the community of faith into the epidemic as part of the prevention. I know that you have been – you certainly are aware of that effort, so what do you think when you now know that the campaign is about to begin?

JOHN: Well, I think it's great that churches are getting involved, that these communities are getting involved. Not just in the black communities, but in the Hispanic communities, the church plays a central role and people trust the church. So the church has very many unique opportunities to do prevention work and to counsel people about getting tested and to draw people into the care system.

JEANNE BLAKE: Robin, when you say that the churches are backing this campaign, what does that mean? What are they doing?

ROBIN: Well, a number of the local pastors' and congregations' names will be listed on the billboard. We have a total of 22 pastors and churches and two other AIDS service organizations that will be listed. It's the first time that they have publicly stepped out individually. I know they've all been doing work in the past, many of them, but individually stepping out and putting their names as a supporter of the Who Touched Me Ministries and their need for services in that community.

JEANNE BLAKE: So it psychologically sends a message that we're all in this together.

ROBIN: Oh, for sure.

JEANNE BLAKE: As Dr. McGuire said earlier, it's such an important tone to set. But if I pick up the phone and I call the number that's on the billboard, which we'll make available on our website – a lot of these resources will be listed -- so if I call that and I want a church within, let's say I live in Dorchester, you'll refer me to a church. But then I go there and then what? What will they do to help? What's the link?

ROBIN: Okay, like you said, the number that's listed is a direct line to the Who Touched Me Ministries at the AIDS Action Committee. They put you in touch with a church in your neighborhood that's in support of what we're doing. By no means would we refer you to a church that's not participating in this program or campaign. And the churches who are in support of it have a number of referrals and resources that are available in our neighborhoods to provide AIDS services as well as any services that their own congregation will be providing, whether that be meals, transportation, prayer partners, visitations from their missionaries ... a number of different services will be provided, so depending on the particular congregation in that neighborhood will depend on the services that will be provided.

JEANNE BLAKE: John, this is a unique way to reach the really hard to reach. In 20 years in the epidemic we know that there are many, many thousands of people who are living with HIV who may not know it, but even if they know it don't feel safe enough to let their status be known and to reach for help. Why do you think that the church can play such a unique role within the communities, particularly here in Boston, but I think in other parts of the country it's true as well. What is the unique characteristic that they have?

JOHN: Well, for one thing the church has access to a lot of people. People that are AIDS service providers, public access to public health departments, and the church is highly regarded and trusted in the community and so it has an opportunity that the rest of us don't have of reaching those people. The church, because of the faith-based environment of the church, I think people who might be alienated or people who might not want to get tested or might not want to get into care because of the stigma that's attached to this disease, I think the church can play a role in drawing those people in without further stigmatizing them.

JEANNE BLAKE: I think that's a really important point. Robin, you said before that there won't be that judgment. Have you collectively met with all of the ministers and representatives of these communities to make sure that there won't be a judgment or stigmatization that comes with it?

ROBIN: Out of the majority of those pastors who are involved, I have been with on an individual basis, and not only have I met with them but this has been presented here in Boston, so they are aware of the criteria and what we are expecting. And I think once they realized what we were looking for as partners and supporters of this campaign, that is what encouraged and motivated them to be a part of it. Because they are ready to provide the services and provide Who Touched Me Ministry to those in need.

JEANNE BLAKE: What kickoff do you have planned?

ROBIN: We are expecting to have the billboards go up July 22. Unfortunately, we will not have a press release that day due to the Red Sox having their memorial ...

JEANNE BLAKE: Ted Williams?

ROBIN: Yes, correct. But we will have a press release unveiling the billboard somewhere around that coming weekend thereafter. So we will have a press release. There will also be a number of pastors and churches in attendance to show their support again. Not only in signing to be a part of the billboard, but to show in their attendance that they are willing to be a partner and back us up.

JEANNE BLAKE: Will there be preaching in the churches from the pulpit about HIV and AIDS as part of this campaign?

ROBIN: There will be announcements made from the pulpit that the billboards are going up, and a number of the members in the congregations are aware that their pastors and churches are in support of this. So there will be some that will be surprised that will see their names of their church and their pastor listed on billboards, but I think it will be a pleasant surprise.

JEANNE BLAKE: Well, it seems to me that it will help pave the way for more people to be open about their status and to reach for help for the first time. I want to thank you, Robin, for coming in. John, thank you for coming in and talking about it. We appreciate it. I'm Jeanne Blake. I'll see you next time.

About Health TV is sponsored in part by
Harvard Pilgrim Health Care Foundation.
Improving health through medical education,
clinical research and community service.