



## Medical Hero in the Spotlight

# Healthy Volunteer wants to be part of the solution

**M**ichele Bailey is committed to finding a cure for HIV. Michele's not a researcher or a doctor. She doesn't suffer from the disease. But when Michele had an opportunity to participate as a healthy volunteer in a five-year study of a potential HIV/AIDS vaccine, she jumped at the chance. She wanted to be part of the solution.

"I was delighted," says the Durham, N.C., resident, who was 39 at the time. "I realized that that kind of study was not for everyone. A lot of people couldn't commit for that long a period of time. It made me really happy that I could. I'd never been in a research study before. I'm not sure I'd even considered it. But I knew the day we licked HIV would be a glorious day and I wanted to participate."

### The commitment

In August 2003, Michele was accepted into a Phase 1 study to test the safety and tolerability of a three-dose regimen of a vaccine being tested at eight sites worldwide. Michele was one of 92 healthy adults enrolled at the University of North Carolina Chapel Hill.

Michele knows that many people would be leery of participating in an HIV vaccine trial: the disease is misunderstood and the web and media have fueled misguided fears about vaccines. But Michele had spent more than a decade working as a public information specialist fielding calls to the CDC's National HIV and AIDS Hotline and later to its immunization hotline. She knew those concerns were unfounded.

She'd also spent a lot of hours working as a community volunteer trying to raise awareness about HIV. "Everybody is involved in something in their community," she says. "It might be the arts or science. The thing I was doing was HIV-related work. I understood what HIV was and what it wasn't. A lot of people have fears and misunderstandings about HIV and fears about vaccines, but since I'd worked in both sectors of public health I didn't."

Over the next five years Michele visited the research clinic at UNC many times. During those visits, researchers bent over backwards to make sure she received the best possible care. "The people at UNC are really warm and wonderful," she says. "They really care about their patients and I was always treated like a member of the research team."

Although Michele admits she was disappointed that her trial didn't find the cure for HIV, she now knows that research isn't just about finding cures: it's about learning and slowly, systematically chipping away at a problem.

Far from discouraged, her experience led her to enroll in additional studies, to join clinical trial community advisory boards and to take a research-related job at the UNC Medical Center.

Looking back, Michele says she is proud to have played a role in helping to combat HIV. "Not everyone is lucky enough to be a healthy study subject," she says.

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# A Guide to Clinical Research

Clinical research is different from traditional “standard of care” medicine. When patients visit their doctor in a traditional setting, they’re seeking a cure for what ails them.

When volunteers participate in a clinical trial, they’re helping researchers answer a scientific question.

We must thank the heroes who volunteered to test the allergy pills that ease our seasonal hay fever. Thank the heroes who tested the pain relievers that soothe our aches and pains. Thank the heroes whose courage has led to enormous strides in treating leukemia, breast cancer and other life threatening conditions.

If you’d like to celebrate these medical heroes and learn more about participating in clinical research, please consider joining us via webcast on November 6 for National Clinical Research Education Day. The webcast, which sponsors are making available in churches, libraries, businesses and medical facilities across the country, will enable you to learn more about the importance of clinical research volunteers and the vital role they play in advancing our scientific understanding.

“The decision to participate in clinical research is a very personal one,” explains Ken Getz, founder and chairman of CISCRP. “Our goal in sponsoring National Clinical Research Education Day is to raise awareness about the importance of clinical research and to help people better understand the process so that they can decide whether or not participating is right for them.”

Webcast viewers will learn about the potential risks and rewards of participating in trials. They’ll learn about the different types of trials researchers conduct, the terminology they use, the safeguards in place to protect patients and the key players involved in the research process.

They’ll also learn about the questions they need to ask and the issues they should consider before volunteering for a trial. Webcast viewers will also hear from a panel of research volunteers about their own experiences with clinical trials.

“As children we learned from story books that heroes are brave,” Getz says, “but in real life, medical heroes must also be knowledgeable. They need to know themselves and understand the research they are participating in. They need to know what their rights are. Real life medical heroes have a choice – they don’t have to participate in research – and that is what makes them so incredibly special.”

## EDUCATION BEFORE PARTICIPATION

- **Get the facts on clinical research**
  - What is clinical research?
  - What are the different kinds of studies?
  - Who is involved in clinical research?
- **Think about questions you should ask and the answers you might get**
  - Consider why or why not to volunteer
  - Be a part of National Clinical Research Education Day
  - Visit <http://www.ciscrp.org/patient/aware/webcast.html>



# Participants play a unique role in educating the public about research

**A**re you a medical hero? If so, tell your story. Share it with your neighbor. Mention it with the person who cuts your hair. Talk about it with your sister-in-law, the guy in the next cubicle at work, or members of your church congregation.

As a medical hero, you are an ambassador for clinical research. Your first-hand experience makes you a valuable source of information for others who might not know much about the trial process. While your participation in a research study may have ended, you can still play an enormously important role in advancing medical science by helping inform and educate people about clinical research participation.

When your friends and family hear about your experience, it encourages them to think about clinical trials in a new light. Research is no longer a far away abstraction conducted by white-coated clinicians in a lab or a clinic. It's something that involves everyday people like you and – maybe – them.

Real-life testimonials are extremely powerful, that's why CISCRP has asked four research volunteers to share their stories as part of the National Clinical Research Education Day webcast, which will be held November 6.

They'll talk about how their friends and family reacted to their decision to participate in trials, why they opted to participate in a trial rather than receive standard of care treatment and offer advice about participating.

Kymone Freeman will share his story about wanting to help find a vaccine for HIV/AIDS. A healthy volunteer, Kymone had seen his uncle die from AIDS. During a trip to Kenya he saw the devastation of the pandemic.



Kymone

“Seeing people who were dying without comfort and beyond help was unbearable,” he said. Kymone will talk about how his decision to participate impacted his relationships and what he learned from the experience.

Liz and Jay Scott will talk about how experimental treatments gave them three and a half more precious years with their daughter, Alex, after traditional cancer therapies failed. They'll also share Alex's brave story about wanting to help others. During her short life Alex, who died in 2004 at age eight, raised tens of thousands of dollars for “her doctors” by selling lemonade. As she explained, “All kids want their tumors to go away.”



Liz and Jay

Peggy Willocks, who suffers from Parkinson's Disease, will talk about wanting to be around to play with her grandchildren. For her, the decision to participate in experimental surgery and her on-going efforts to promote research, are a way of standing up to her disease.



Peggy

As for Jenna Korb, she's living proof of the life-saving potential of clinical research. In 1993 as a 19-year-old college student, Jenna was diagnosed with leukemia and her prognosis was dire. Jenna says participation in a research trial for an anti-rejection drug, which is commonly used today, helped save her life in the wake of a bone marrow transplant.



Jenna

While these powerful stories will be shared with webcast viewers around the country, your story is just as important and powerful; particularly to the people who know you. Kymone, Alex, Peggy and Jenna are heroes. So are you. Tell your story.



# National AWARE Day – Don't miss it!



## National **AWARE** *for All*



### Is Clinical Research Right for You?

Come and find out at AWARE for All,  
a free clinical research information  
event for the public.

### Clinical Research Education Day

A LIVE WEBCAST—SATURDAY, NOVEMBER 6, 2010

12:00 PM–2:00 PM EST • 11:00 AM–1:00 PM CST • 10:00 AM–12:00 PM MST • 9:00 AM–11:00 AM PST

#### Highlights of the Day

- Live national webcast
- Open to the public
- Bring your friends and family
- Information and Exhibit Area
- Hear stories from patients who have participated in clinical research

#### At the program you will:

- Learn what clinical trials are and how they work
- Learn why society needs clinical research
- Understand the safety, benefits and risks of clinical research
- Learn questions to ask your doctor or healthcare provider before participating in clinical research.



CISCRP is an independent nonprofit organization dedicated to educating and empowering people to make informed decisions regarding participation in clinical research. CISCRP does not recruit patients for clinical trials and does not conduct clinical trials. For more information about CISCRP, please visit [www.ciscrp.org](http://www.ciscrp.org) or call 1-877-MED-HERO.

Registration for this program is free.

To find a site near you visit [www.awareforall.org](http://www.awareforall.org) or call 1-877-MED HERO.

This program is being sponsored in part by an educational grant from **genzyme**



## Register today



*Volunteers in clinical research are the heroes in the discovery of new medical treatments*