ACTG

AIDS CLINICAL TRIALS GROUP

Update

December 2012 Volume 1 Edition 2

Tropical Storm Sandy Impacts Sites Worldwide

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ACTG Still Struggles in Sandy Aftermath

Four Network Members Share Their Stories

Days before the AIDS Clinical Trials Group Network's Leadership Retreat was slated to start on Oct. 31, Hurricane Sandy began her unsteady path up the eastern seaboard. Unclear as to where and when she would make landfall as well as if she would be at hurricane or tropical storm strength, the ACTG's international travelers began boarding their flights from Africa to the United States. Researchers, site staff and Community Advisory Board members stateside in New York City wondered if Sandy would be another much hyped about, but lackluster storm like Hurricane Irene had been nearly a year prior. No one envisioned that the largest Atlantic tropical storm in history would slam into the United States' most populous city, wreaking havoc on ACTG Network members' personal and professional lives around the globe. Below are stories from four of the many folks impacted to this day by the storm and the lessons they've learned in case history repeats itself.

Judy Aberg, MD, Principal Investigator, New York University School of Medicine/Bellevue Hospital HIV/AIDS Clinical Trials Unit, New York City, NY, USA

"I remembered stocking up in advance of Irene the summer before and nothing happened," Aberg says during a phone call from her faculty housing on the 23rd floor of New York University's School of Medicine's campus on Monday night, Dec. 3. In addition to her ACTG role, Aberg is Director of Virology at Bellevue and the Director of the Division of Infectious Diseases and Immunology at New York University's School of Medicine. "I told friends and colleagues if things got really bad this time, they could come over and I had vanilla Oreo cookies and cheese 'n crackers ready to go." Sadly, she did stock up on real food, like sandwiches, which all perished.

A photo Aberg shot of her team using headlamps and flashlights to save ACTG samples from her lab.

The cover photo is a shot Aberg took from her 23-story apartment on NYU's campus as the East River spilled over the FDR.

But when the storm didn't hit New York City on Sunday night, Aberg and her colleagues returned to the hospital to see patients at Bellevue Monday. Bellevue Hospital leases space to NYU investigators like herself to conduct her administrative, outpatient and research endeavors. Aberg's office was on the fifth floor and her lab above and her outpatient services were one floor below in an adjacent building. Tropical Storm Sandy hit Monday night with incredible winds during high tide and a lunar high tide at that. Aberg watched in horror as the Franklin Delano Roosevelt East River Drive (the FDR) separating NYU and the East River was breached by 18-foot waves.

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Spotlight on Service: ACTG's Site at Boston Medical Center

From left to right: Meg Sullivan, MD, Medical Director of the Center for Infectious Diseases at Boston Medical Center; Glory Ruiz, Practice Manager of the CID at BMC; and Benjamin Linas, MD, MPH, CID Physician and Associate Principal Investigator of the Boston Medical Center AIDS Clinical Trials Unit.

One-stop shopping. It's a simple motto, the staff at Boston Medical Center (BMC) use to describe the services they offer at the Center for Infectious Diseases. Yet the list of HIV resources available to the community is entirely comprehensive, encompassing a laundry list of every possible need a person with HIV could encounter on their pathway to disease management.

"It feels good to work in this environment," says Benjamin Linas, MD, MPH, Associate Principal Investigator of the Boston Medical Center AIDS Clinical Trials Unit, which is part of the AIDS Clinical Trials Group Network. Linas wears the hats of a provider in the Center for Infectious Diseases and a researcher in HIV trials at BMC. Therefore, he works closely with the clinical side, where testing begins.

Taking the Test

If you are unsure of your HIV status, the Center for Infectious Diseases at BMC offers walk-in, free and rapid HIV testing with results in 20 minutes. There is also sexually transmitted disease testing with expedited results and on-site treatment. Locations include the Center for Infectious Diseases clinical offices on the ninth floor of the Shapiro Center at 725 Albany Street on BMC's main campus and at the store front walk-in center called Project Trust at 721 Massachusetts Avenue. On-site testing is also available through the testing program in BMC's primary care, obstetrics and gynecology, urgent care, emergency medicine and women's care practices. During World AIDS Day on Dec. 1, and National HIV Testing Day on June 27, BMC staff head to shelters and college campuses to test residents and students.

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A5199 Yields Neurology Benchmarks

Johnstone Kumwenda, FRCP, remembers presenting at the first AIDS Clinical Trials Group meeting after his site in Blantyre, Malawi, had been officially incorporated into the Network. When he took to the podium, he did not know his talk would foster a collaboration that would lead to a study in HIV and neurology in a limited-resource setting. In the audience listening to his presentation that day in 2003 was Kevin Robertson, PhD, Principal Investigator at the ACTG's site in Chapel Hill, NC, USA.

The Africa NeuroAIDS meeting in 2004 was also the kickoff for A5199 in Africa. Many of the investigators from A5199 were there, including Robertson, fifth from the right, and Kumwenda, third from left.

"Dr. Robertson pulled me aside about conducting a study exploring neurology and HIV in a limited-resource setting since that had never been done before," Kumwenda says.

Kumwenda was one of the international principal investigators gearing up for participation in A5175 or the PEARLS study. The Prospective Evaluation of Antiretrovirals in Resource Limited Settings (PEARLS) was conceived with a goal of testing the safety and efficacy of initial treatment in a culturally diverse population. Robertson envisioned a way to gather neurology benchmarks for HIV positive participants through A5175 by following the study volunteers in six of the seven international countries in a separate study piggybacked onto the parent PEARLS study. Building off of this initial meeting, A5199 or the International Neurological sub-study was born.

"I remember giving a five-minute proposal of A5199 to convince the A5175 principal investigators to do this as a sub-study," Robertson says. "It was well-received and what made it work was that NIMH (National Institute of Mental Health) supported the study. Initially, going forward was a Catch 22 because the ACTG needed external support while the NIH (National Institutes of Health) wanted a protocol prior to funding."

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Enrolling Study A5279 Tests Lower and Shorter Dose of Drugs for Prevention of TB

Richard Chaisson, MD, Johns Hopkins

Tuberculosis is the number one killer of patients with HIV worldwide. This is a fact AIDS Clinical Trials Group's researcher Richard Chaisson, MD, Investigator at Johns Hopkins Adult AIDS Clinical Research Site, had in mind when developing the enrolling study A5279.

"TB infections are an enormous problem globally. There are almost 9 million new cases and more than one million deaths annually," says the study co-chair, Susan Swindells MBBS, Investigator at the University of Colorado. "Preventative TB treatment works very well, but lasts six to nine months and many people don't complete the regimen because it's too long."

The A5279 study team hopes to try a new course of TB treatment for a shorter amount of time and see if they have better adherence rates and similar outcomes to longer courses of treatment. The Centers for Disease Control and Prevention (CDC) funds the TB Trials Consortium, which found that a three-month weekly course of rifapentine/isoniazid was as effective when compared to the traditional nine-month course of daily isoniazid, says Swindells. However, rifapentine is not available in all international sites. Building from this evidence, the A5279 study will explore whether rifapentine and isoniazid taken together daily for one month can produce the same or better results. The official name of their study A5279 is "Short-course rifapentine/isoniazid for treatment of latent TB in HIV-infected individuals."

"We are very excited to be able to study this ultra-short course of treatment for latent TB," said Chaisson. "If successful, this could be a game-changer."

The study will compare traditional latent TB treatment given daily for 36 weeks with the rifapentine/isoniazid combination given daily for one month. Study volunteers are being sought from domestic and international sites.

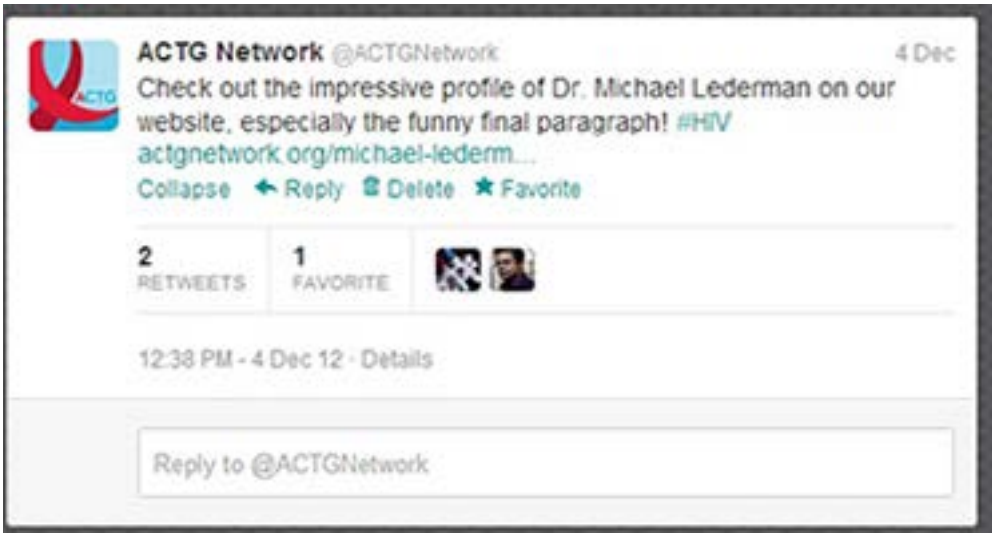
"We want to have representation from areas most impacted by TB including sites in sub-Saharan Africa, South America, Haiti, India and Thailand," says Swindells says. "The endpoint for TB trials is to see who develops TB and from which arm of the study. This is an important study and our goal is to change prophylactic therapy."

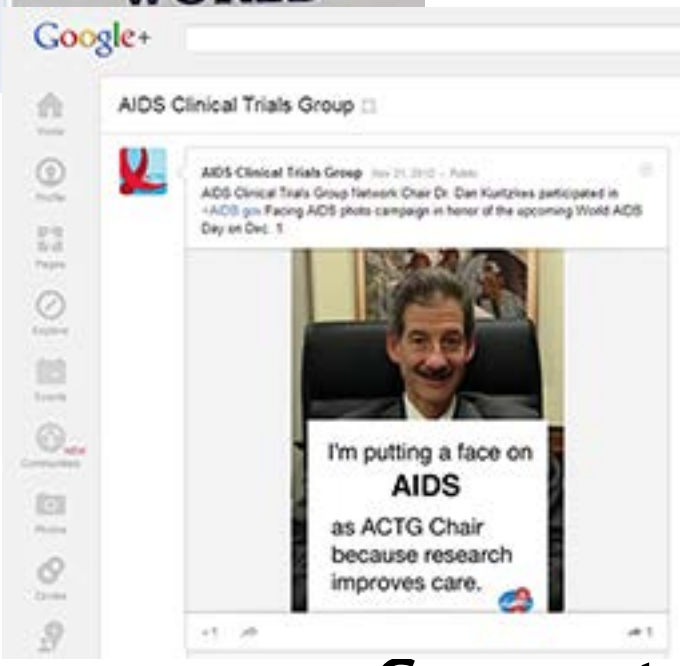
The study will run for three years. Antiretroviral (ARVs) naive participants as well as some on ARVs can enroll. A person's CD4 count will be taken into consideration. Domestic sites will test potential study volunteers for latent TB infection, but not in high burden sites, Swindells says. Chaisson is Chair of the ACTG's Tuberculosis Transformative Science Group, and Swindells is a member and also Protocol Facilitator for this group. More information can be found at study volunteers' local sites.

Susan Swindells, MBBS, University of Colorado

Don’t Miss the Conversation Online

The ACTG has embraced social media and if you have a Facebook, Twitter or Google Plus account, we invite you to interact with us online! You can also always watch our 10 videos on our YouTube channel without having any sort of personal social media presence. Here are some of the conversations you might have missed if you are not a fan of the ACTG on Facebook, a follower of the ACTG on Twitter or in our circles on Google Plus: World AIDS Day photo slideshows from ACTG sites on Facebook, the Berlin Patient Timothy Ray Brown’s visit to the San Diego CAB on YouTube, Dr. Michael Lederman’s ACTG website spotlight hits it big on Twitter and ACTG Chair Dr. Dan Kuritzkes’ AIDS.gov Facing AIDS campaign photo is shared on Goolge Plus!





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Spotlight on Service: ACTG's Site at BMC

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"We are the largest reporting site in the state for new HIV positive results," says Glory Ruiz, Practice Manager of the Center for Infectious Diseases at Boston Medical Center. "Because we are funded by the state to offer the rapid HIV test, we cast a wide net both on and off campus. You do not have to be a BMC patient to use our services. But when you walk in, we give you the red carpet treatment. And if you test positive, we make your HIV care as barrier-free as possible."

If your HIV test comes back positive, you are immediately surrounded by a support team, including a nurse, case manager and a peer navigator who is HIV positive.

"When the clinic is open, we escort anyone with a reactive result to the team," says Ruiz. "We begin services on the spot like getting your baseline labs, offering you mental health resources and assisting you with disclosure. It's so important that we have a peer navigator because they connect with patients on a different level because they can talk about their own HIV experience."

This initial meeting is also when a follow-up visit with an infectious disease physician like Meg Sullivan, MD, Medical Director of the Center for Infectious Diseases at Boston Medical Center, is scheduled. In the interim between a positive diagnosis and the follow-up appointment, the peer navigator is in frequent contact with the patient ensuring housing, financial and legal issues are not obstacles to care.

"Identifying barriers to infectious diseases treatment starts at intake," says Sullivan. "You don't need to get your HIV care from BMC even if you test positive here. We are willing to refer you to a facility closer to home if that is necessary. However, the medical home approach to care is becoming increasingly popular and is the one employed in the Center for Infectious Diseases at BMC. That is the model in which the primary care physician and a specific team including a nurse and a case worker follow you throughout your care. But when it comes to HIV treatment at BMC's Center for Infectious Diseases, this medical home approach is what we've been doing for 18 years. An ID physician, like myself, plays the role of the primary care provider and then a patient is matched with a specific nurse, case worker and peer navigator. Since it's always the same team that you see, we build close relationships with our patients and see better adherence to medicines prescribed and appointments scheduled."

Beyond the Initial HIV Positive Diagnosis

Being situated in an urban area, Linas says mental health, OB/GYN, substance abuse and co-infections are extremely common among patients living with HIV at BMC. Infectious diseases staff work with all the other departments within BMC's walls to connect their 1,500 patients with care for their overall well-being.

For example, Sullivan says that each week, her infectious diseases colleagues head over to OB/GYN to treat HIV-infected pregnant women receiving prenatal care at BMC.

"We can travel to them," Sullivan says. "A pregnant woman with HIV, especially with other children in tow, should not have to walk over to ID for care. We come to them and we've seen that this service has increased

adherence as well."

Linas cites substance abuse and mental health as two areas where he is really impressed with the continuity of care. Alex Walley, MD, is a primary care physician who focuses on infectious diseases and substance abuse. "There is no referral needed to see Alex so we notice that his patients keep their appointments for management of their HIV and substance abuse," Linas says. "Alex also takes the medical team approach to care and his wing woman is a licensed addiction counselor."

Sondra Crosby, MD, is a physician in the infectious diseases team who specializes in the care of immigrants and refugees who may have become positive due to rape and torture in their native country. Patients come to BMC from multicultural backgrounds and staff in the Center for Infectious Diseases speak 13 languages. "We are a diverse staff and that reflects the patients we serve," says Ruiz. "It's what separates our clinic from the other options in Boston. We have fine-tuned our services to really provide a community-based approach."

HIV Research at BMC

The research site at BMC seeks to be a leader in conducting HIV-related investigations in a U.S. urban context, with a particular focus on HIV/HCV (hepatitis C virus) co-infections, women's health and tuberculosis.

"Because we see a lot of substance abuse and poverty in the Greater Boston area, we have many patients with HIV and HCV or HIV and TB co-infections," Linas says. "The research protocols are open to patients we see in clinic and the hospital, and they provide our patients access to the latest and best therapies. We work tirelessly to gain the trust of our patients such that they are willing to enroll in a clinical trial, but once they are in a study, they stay in."

Linas attributes the success in clinical trial participant follow-through to the familiar faces patients see in the clinic in the Shapiro Building and the research site in the Dowling Building on BMC's campus. "Our staff, especially our nurses, go back and forth between the clinic and our research offices so we are able to buck the stereotype for follow-up in clinical trials because there is that sense of trust. Patients know us and we are able to bridge that gap both physically, because our spaces are close in proximity to each other, and medically," Linas says.

In comparison to the hustle and bustle of the clinic, Linas admits most patients who make the commitment to also be in a clinical trial at the ACTG's BMC site find the research offices calming, almost a Zen-type atmosphere. There are three protocols open for enrollment currently at BMC, including A5294 (HIV/HCV) and A5279 (Latent TB), A5298 (HPV/HIV), and soon, A5308, headed by Paul Sax, MD, an ACTG researcher down the street at Brigham and Women's Hospital. A5308 will explore Truvada on HIV patients who are elite controllers of the virus. Learn more about A5279 in this newsletter's enrolling study spotlight.

Under the Partners/Harvard AIDS Clinical Trials Unit, Boston and Providence have five sites for clinical trials in the ACTG Network. Linas says he and the other researchers in the area, like Sax, can easily collaborate. And the HIV patients in the area are no stranger to the benefits that can come from being a part of research since trial recruitment is common. "Our patients get a lot of extra attention and high quality care nowadays," Linas says. "And because there is now an established history of safe and effective trials being conducted at BMC, patients are not as fearful to enroll in a trial in 2012 when compared to trials years ago."

For more information about the clinical and research services provided by Boston Medical Center's Center for Infectious Diseases, visit their website at http://www.bmc.org/infectious-diseases.htm.

A5199 Yields Neurology Benchmarks

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Together, the principal investigators of both A5175 and A5199 began site trips. In 2004, Robertson remembers all of the African A5199 investigators attending one of the first NeuroAIDS in Africa meetings along with other researchers in sub-Saharan Africa.

“There was this overarching need for HIV and neurology information from countries other than the United States, Europe and Australia,” Robertson says. “We needed information from countries where there were different clades or subtypes of the virus that would then lead to different neuropathology. In limited-resource settings, there was also a lack of treatment for opportunistic infections and HIV-associated cognitive dysfunction.”

“The international sites only had anecdotal information when we asked them about neurologic diseases they were seeing,” Kumwenda adds. “There was no systematic review to categorize neurological issues and functional issues like cryptococcal meningitis.”

Since almost all of the international sites did not have a neurologist on staff, Kumwenda and Robertson saw an opportunity to train site staff in neurological testing, which could benefit the sites after this particular study completed. The international sites in A5199 include Blantyre and Lilongwe in Malawi, Chiang Mai in Thailand, Rio de Janeiro and Porto Alegre in Brazil, Pune and Chennai in India, Lima in Peru and Johannesburg and Durban in South Africa. After 192 weeks on study, 342 participants still remained in regular contact.

“This is a substantial group of participants and we attribute this amount of follow-up to the sites and the excellent work they did in becoming trained in conducting neurological exams,” Robertson says.

The conclusion of A5175 showed that a tenofovir-based regimen of antiretroviral treatment (ART) was less toxic than two other combinations being used. In Malawi, Kumwenda says this result lead to the government’s decision to use the tenofovir-based regimen as the first line of treatment in pregnant women.

Being a sub-study of A5175 allowed Kumwenda and Robertson to gather the first benchmarks for the neurological impacts of HIV in a limited-resource setting. However, since the participants in A5175 were relatively healthy, Robertson would like to conduct further research into participants who have more HIV systemic disease, and in those who are HIV seronegative.

“If we can get that information on HIV seronegatives, we can determine a normal benchmark for neurological disorders in HIV patients in resource-limited settings,” Robertson says. “To get this information, we have almost fully enrolled our next study A5271. Then we can compare the data from A5199 and A5271 to put the data from A5199 in context and have this normal benchmark available for future clinical and research studies around the world.”

Robertson, Chair of the ACTG’s Neurology Collaborative Science Group, says his fellow neurologists would like to see another study exploring whether earlier initiation of ART has an impact on neurological dysfunction, such as staving off the cognitive changes associated with HIV including problems with attention, learning and memory. He is grateful A5199 has started the ball rolling into the future of HIV and neurological studies in limited-resource settings. “Being able to conduct A5199 as such a huge study across the world would not have been possible without the ACTG infrastructure and the dedication of the international sites,” Robertson says. “I marvel at the great work they did.”

“I echo that,” Kumwenda adds. “It was a huge undertaking, especially for the sites to learn how to conduct detailed neurological exams. The spin-off is that now Kevin and other neurologists can use this data and continue conducting studies like the one they are embarking on with A5271.”

ACTG Still Struggles in Sandy Aftermath

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Once she realized Tropical Storm Sandy was packing a much bigger punch than Hurricane Irene the summer before, she and her staff sprang into action and it's a stance they continue to take and will be forced to endure as their site is not slated to be reopened until March 2013 at the earliest.

"You know, I think there are actual New Yorkers who don't even understand right now how bad it was and still is," Aberg says with a weary laugh on the phone, tucked away for a few minutes in the now quiet, power-restored apartment on NYU's campus. "Most days, I am in a hallway sitting on the floor of the Bluestone Center at the Dental School or the Translational Research Building where we now rotate times to share the space with other displaced investigators from NYU. It's noisy and I have to join Network leadership calls using my Blackberry and keeping myself on mute so that background sounds aren't picked up during the call. Dan (Kuritzkes, MD, ACTG Chair, Brigham and Women's Hospital, Boston, MA, USA) and Judy (Currier, MD, MSc, ACTG Vice Chair, UCLA, CA, USA) must think I have nothing to say on calls anymore, but I really do!"

Another shot taken as Aberg's team tries to rescue samples. She didn't use the flosh on her camera in this shot and it shows how dark the room really was as her staff worked quickly to save what they could.

When you get Aberg talking about those first few days after the storm you begin to sense the desperation she and her colleagues and staff faced as they fought the elements and put their personal safety at risk to save patients' lives, medications and records as well as years of research, lab animals and specimens. Unable to shower and climbing up and down 16 flights of stairs to round on patients while her staff were passing fuel up 13 flights of stairs to get generators working and food trays up 21 stories, Aberg and her colleagues lived off of those cookies and crackers she had stocked up on and faced each other in the halls late at night, many post-doctoral fellows breaking down when they realized their work was lost.

"On Monday night, Oct. 29, evacuating patients at NYU was the priority and many helped the New York Fire Department (NYFD) get patients to safety," Aberg recalls.

The following day, Bellevue had no water and the evacuation of Bellevue's 725 patients required help from the National Guard as well as the NYFD.

"We really thought this would only be a problem for a couple of days, but by Wednesday, Oct. 31, we began packing whatever samples we could in dry ice because my minus 80 degree refrigerators had warmed up to minus 49 degrees," Aberg says. "By the next day, the freezers were 4 degrees and all remaining samples were lost. We carried 20 pound bags of dry ice the five blocks between NYU and Bellevue wearing head lamps up the stairs to light our way and then carried the samples back to be shipped off in minus 80 freezers or liquid nitrogen. In one lab we went into it was like walking through a giant slushy."

Up the street, NYU lost 70 percent of its animals since they were housed in the basement. Everyone was devastated by the loss, Aberg says. On Oct. 31, she ventured out in search of a shower.

"On Halloween night, I walked, flashlight in hand, to 41st Street to shower at a sports club up there and I was so surprised to see so many New Yorkers a few blocks away partying for Halloween while we were hungry and grubby trying to save our work," Aberg recalls. "We were worlds apart."

And then Aberg started receiving texts about what she thought of Mayor Michael Bloomberg and the New York Marathon. Having had no electricity for days, she initially had no idea what people were talking about.

"Because I had no power, I hadn't seen the news," Aberg says. "I thought, 'What is the big deal? Who cares whether they have a marathon?' It was the last thing on my mind. It wasn't until a meeting on Nov. 2, when someone handed me a newspaper from the day before and I learned that Bloomberg was proposing using the generators in Central Park for the marathon and all these neighborhoods were totally destroyed. I quickly jumped on my phone texting to everyone how bad of an idea that was!"

Patricia Bartlett, LICSW, Duke University, Durham, NC, USA and Kilimanjaro Christian Medical Clinical Research Site, Moshi, Republic of Tanzania, Africa

"I am based in both Tanzania and Duke," writes Bartlett in an email on Tuesday, Nov. 20. "Duke was not impacted at all by Hurricane Sandy. My husband [John Bartlett, MD, Duke University Medical Center HIV/AIDS Clinical Trials Unit] was to attend the leadership retreat and so he was impacted by not being able to attend."

But Bartlett had another person on her mind for the days leading up to and during the aftermath of Sandy – Kilimanjaro Christian Medical Clinical Research Site's new Community Scientific Subcommittee representative, who already boarded the plane from Moshi, Tanzania to Amsterdam, The Netherlands, when the storm forced the ACTG leadership to cancel the retreat.

"Despite our attempts to work through Delta/KLM to send her back to Moshi, the airlines refused to contact her in Amsterdam," Bartlett recalls. "Thus, she was sent on to Washington, DC. Though our Moshi site had sent her with money for cab fare to the hotel and for the first night, there was no way to predict that she would need more or to give her money for the entire trip. In addition, she did not have an international phone, which left her with no way to receive or send information."

Vinny Parrillo, Cornell Clinical Research Site Patient Advocate and Community Advisory Board Member, New York City, NY, USA

"We were worried all day listening to the news – subway shut downs and tunnels closing," writes Vinny Parrillo, Cornell Clinical Research Site Patient Advocate and Community Advisory Board Member, New York City, in an email on Nov. 19. "But we were very concerned when Con Edison of New York did not shut off power to all of New York City for awhile until after the tide surge. If they had done that, like they did for Wall Street, we would have had power restored much quicker."

Instead, Parrillo says, Con Edison left the power on and when the tide rose, a huge bomb-sound was heard. "We did not see the light blast from this until a week later when power was restored, but it was huge and a few blocks from my home," Parrillo says. "The waters rose up to 20 feet from my home. But since we had our heater and hot water tank moved to first floor 30 years ago, we had hot water, gas to cook and drinking water. Power went down for only a week, and the day before the storm I was lucky to have bought two LED flashlights."

These flashlights helped Parrillo travel to lower Manhattan, where there were no street lights or traffic lights for days. He was also able to navigate the darken streets to his car, where he used his car charger to power up his phone and then walk to Times Square to get cell service.

Luis Lopez-Detres, Regulatory/Outreach Coordinator, Cornell Clinical Research Site, and personal residence in Zone A, Lower Manhattan, NYC, NY, USA

"I live in Lower Manhattan, next to the FDR, north of the Brooklyn Bridge," writes Luis Lopez-Detres, Regulatory/Outreach Coordinator at Cornell's Clinical Research Site, in an email on Monday, Nov. 26. "My zone was Zone A, and where I live, we were asked to evacuate. However, most people did not evacuate, thinking it would not be so bad. Close to midnight on Tuesday morning, Oct. 30, I saw the river flooding the building that was closer to the river and the parking lot."

Twenty minutes later, Lopez-Detres says the power shut down in Lower Manhattan. Two days later, he had to leave his 17th-story apartment, since he could not flush the toilet and the food in the refrigerator could no longer be eaten. The elevators were not working. Everything was dark.

"But people did what they could with candles and flash lights," says Lopez-Detres. " I stayed for a week with friends, that had power, and were generous and treated me with an incredible kindness. I needed their power because I had to use my cell phone. My father was dying in Puerto Rico, and I had my brother and sister calling me to tell me what was going on down there. Because of the storm, I could not make it to Puerto Rico, to see my father – dead or alive."

Aberg and the Aftermath

Her resiliency is clearly fueled by a healthy sense of humor as Aberg continues with the most recent updates to the NYU, Bellevue and Veterans' Affairs ACTG locations. She is sharing space until further notice with investigators at the Bluestone Center at the Dental School and at the office of Jeff Greene, MD, who had just been named the Director of the Infectious Diseases Faculty Group Practice at NYU before the storm, but luckily hadn't moved his office yet, allowing her to use one of his exam rooms to conduct HIV Vaccine Trial Network (HVTN) study visits.

Another shot of Aberg's unit captures the darkness and desolation of what should be a busy floor at Bellevue Hospital.

"I am happy to report that despite it all, we have not had a missed visit or a visit out of the study window," Aberg says proudly. "We have caught up with our queries and we were even able to go back a couple more times to our old offices at Bellevue with a security escort and get more of our charts."

She is still facing hurdles – mostly in the form of drawing labs and finding dedicated space and office hours that facilitate all she and her staff need to do each day to keep her research for ACTG and HVTN operating as usual during the most unusual circumstances.

"We are thankful to be housed in these other institutions like the Bluestone Center, Jeff's offices and today (Monday, Dec. 3) we heard that the Ambulatory Care Center at Bellevue was reopening for most services, except HIV. We need to be able to draw our labs at Bellevue, again because that's where I have negotiated rates. Currently, I am paying $410.50 for safety labs when I would normally pay $40.38 at Bellevue."

Aberg also mentions how grateful she is to her colleagues, Trip Gulick, MD, MPH, at Cornell, and Scott Hammer, MD, at Columbia, for graciously offering to help. "Without their help, we never could have been able to complete our study vists and have the appropriate samples processed and shipped," she says.

Since Aberg was in Florida during Hurricane Andrew in 1992 and assisted in the evacuation of Cleveland Clinic Ft Lauderdale Hospital near the beach, she is now somewhat of a storm medical disaster expert and she wants to develop the checklist she wishes she had created after Andrew for quickly and efficiently saving supplies from a lab and research unit.

"I grabbed rectal swabs, but we don't have access to the colorectal surgeon yet," she says with a laugh. "And I left the fetal bovine serum in the freezer because I didn't understand its importance until my lab technician asked me if I saved the FBS so she could start processing our own samples again."

Moving Forward

Bartlett, Parrillo and Lopez-Detres also learned from their experiences. Lopez-Detres said Cornells' phones were not fixed until Monday, Nov. 26, and they, too, lost many refrigerated items.

Bartlett would like to see alternative means of communicating with Network members as they travel internationally explored. Her representative from Moshi was one of several international travelers who eventually made it to Washington, DC. And even though the ACTG meeting had been canceled while they were en route to the United States, Bartlett says this small group bonded.

"The little group of folks who were there talked every day and was very supportive of one another," she writes. "Perhaps for the newer, international ACTG representatives, it was helpful to have veteran members help them not to feel overwhelmed by the science of it all and by the nomenclature that is so foreign. For them, the experience in DC was terrific."

Parrillo sympathized with the international travelers as he was all packed up to head to DC for the leadership retreat when he learned the meeting was cancelled. He reminds everyone that donations to the Red Cross can still be made and that people living with HIV are still struggling to get their medications as pharmacies have been impacted and there are less emergency rooms to turn to when they do get sick because the evacuated patients from NYU, Bellevue and the VA Medical Center are taking up beds that would normally be available.

The underlining final thought from Parrillo, Lopez-Detres, Bartlett and Aberg was one of hope and appreciation for the kindness of strangers.

"I have nothing, but praise for all of the other hospitals in the city who have given us space to see our patients and to all those who reached out to help keep our AIDS Clinical Trials Unit afloat," Aberg says. "I got my first real meal on Thursday, Nov. 8, and I won't be sad if I never see another vanilla Oreo cookie again."

Questions, Comments and Story Ideas

This is the second edition of the ACTG Update. If you would like your enrolling study featured or results from your completed trial highlighted, please contact Morag MacLachlan at mamaclachlan@partners.org. Any questions, comments and story ideas are also welcomed!