Bondi Beach and the Bra Boys

July 30, 2007 By Regan Hofmann

As the International AIDS Conference came to a close this past Wednesday I sat out on the docks of Cockle Bay trying to resist feeding my French fries to the seagulls while reflecting on news I?d heard in one of the final sessions. I?d just seen a presentation of the latest data on testing for a high sensitivity reaction to Ziagen/abacavir, given by the drug?s manufacturer GlaxoSmithKline. To reduce a half-hour presentation into several sentences, scientists have determined that it is now possible to very accurately predict whether or not a patient will have the high sensitivity reaction to abacavir that they have seen in some who take the drug?without having to expose a patient to the drug itself. It?s big news. Even though the high sensitivity reaction happens only in a very small number of patients it can be dangerous, even deadly, if patients stop taking the drug and then restart the drug later. The mere possibility of this has kept people (many unnecessarily) off the drug. The new tests (done via blood or oral swab) would be conducted before a patient went on the drug; the results would help doctor and patient know whether abacavir was a viable option for that patient. I clearly remember talking with my doctor about the potentially adverse reaction that could occur from abacavir. I decided to take the risk (because I understood that it was only if I failed to follow directions and take the medication again after stopping it?if I had been highly sensitive to the drug and that had led to a rash and fever or other less quantifiable side effects?that the drug might hurt me). Still, my doctor and I were really rolling the dice, even though the odds were in my favor that the drug would help me without any adverse results.

I think it is amazing that developments like these are made, but I get frustrated when I hear pharmaceutical companies say that they?re going to focus their marketing efforts around the news of this test only to the physicians. Why not also tell the patients? How about a little direct to consumer messaging, in the form of advertising in print or online to make people aware that their fear of a high sensitivity reaction to abacavir might be unnecessary? Why not let them know that there are tools that can help them make sound decisions about their own healthcare? Looking back on my own apprehension about taking a drug that might have serious side effects and knowing how long it took me to decide to try it, I can?t imagine how much better it would have felt to know whether or not the new drug was going to help me without hurting me.

I?ve heard some of the marketing teams at the pharmaceutical companies (and people at the advertising agencies who work on marketing AIDS meds) explain that direct-to-consumer ads are less necessary now that many of the drugs have been in the market for some time (the thinking is that most people know what?s out there, or, if they?re newly diagnosed their doctor will tell them.) But I think as the pharma companies continue to evolve and improve formulations, there?s even more need to get this news directly to the patients whose lives will be affected so that they can

influence the choice of the drug their doctor prescribes them. People living with HIV?especially those on first-line treatments who are not resistant?have many treatment choices. That?s all the more reason to continue talking with patients directly about care. I trust my doctors very much, but ultimately, the choice on how best to fight HIV should be a combination between his recommendation and my well-informed opinion. I think AIDS patients are among the savviest patients in the world. Pharma ads that address the ongoing evolutions and improvements with their products could have a huge impact on my choice of drug. And the advertising campaigns should be redesigned to speak more clearly about the advantages of their product. If the FDA bans this type of advertising, then we must find other ways to reach out through consumer vehicles like POZ and AIDSmeds to get the info to people living with HIV (as well as to those who choose to support them).

Many of the medical journals received embargoed information from pharmaceutical companies prior to the IAS conference so that the latest news could hit their pages first. I think that?s fine, but it?s my goal to encourage pharma to also give POZ the same embargoed information so we can get it as quickly as possible to those who are actively using?or who are imminently considering using the drugs?like you, our readers. One final observation about the state of AIDS information dissemination: I encountered (well, overheard) some journalists in the media center who were still getting up to speed on their ?reporting on AIDS? skills. One guy from Bloomberg asked what a viral load was. Actually, as the world of AIDS reporting has been largely monopolized by a few select (albeit terrific journalists) I am happy to see other reporters tackling the disease even if they?re still in the learning curve stage. It?s hard to believe, but important to remember, that may of the young budding journalists today have no personal experience with the early days of AIDS in America.

I could go on about what we learned from (and what you?d find most interesting about) the conference, but there?s no need for me to rehash what Peter Staley, Tim Horn and our wonderful video interview subjects have so brilliantly outlined about the latest treatment updates (so please, if you haven?t, read the conference coverage on POZ.com and AIDSmeds.com). One treatment issue I?d like to vent about: I find it frustrating when certain key studies fail to produce results that are dramatic enough to be ?conclusive? because by providing all the necessary support that we must when testing, for example, PrEP or the efficacy of a diaphragm in women to block HIV infection (did you know that most HIV infection in women happens via the cervix rather than the vaginal walls? That was news to me!), we end up preventing the HIV infections (a good thing of course!) in the control arm. If infections in the control arm were un-prevented, we might see more dramatic results?the kind that show efficacy. The ironic thing is for these trials to work, they must show some failure in the control arm and that?s less likely to happen when you also provided people with education, condoms and other appropriate measures to ensure their safety. What a twisted up system: in trials designed to prove that PrEP and diaphragms work, we need to show that people get infected when they don?t use PrEP, or diaphragms, but it would be inhumane to allow people in these trial not using the prevention measures the study is set up to test to become infected, so we reduce their potential risk of infection with education, therapy and condoms, and, as a result, most participants stay healthy and we can?t say that we have conclusive evidence about whether the new prevention methods work. It?s a dilemma for sure. I?m sure I sound so

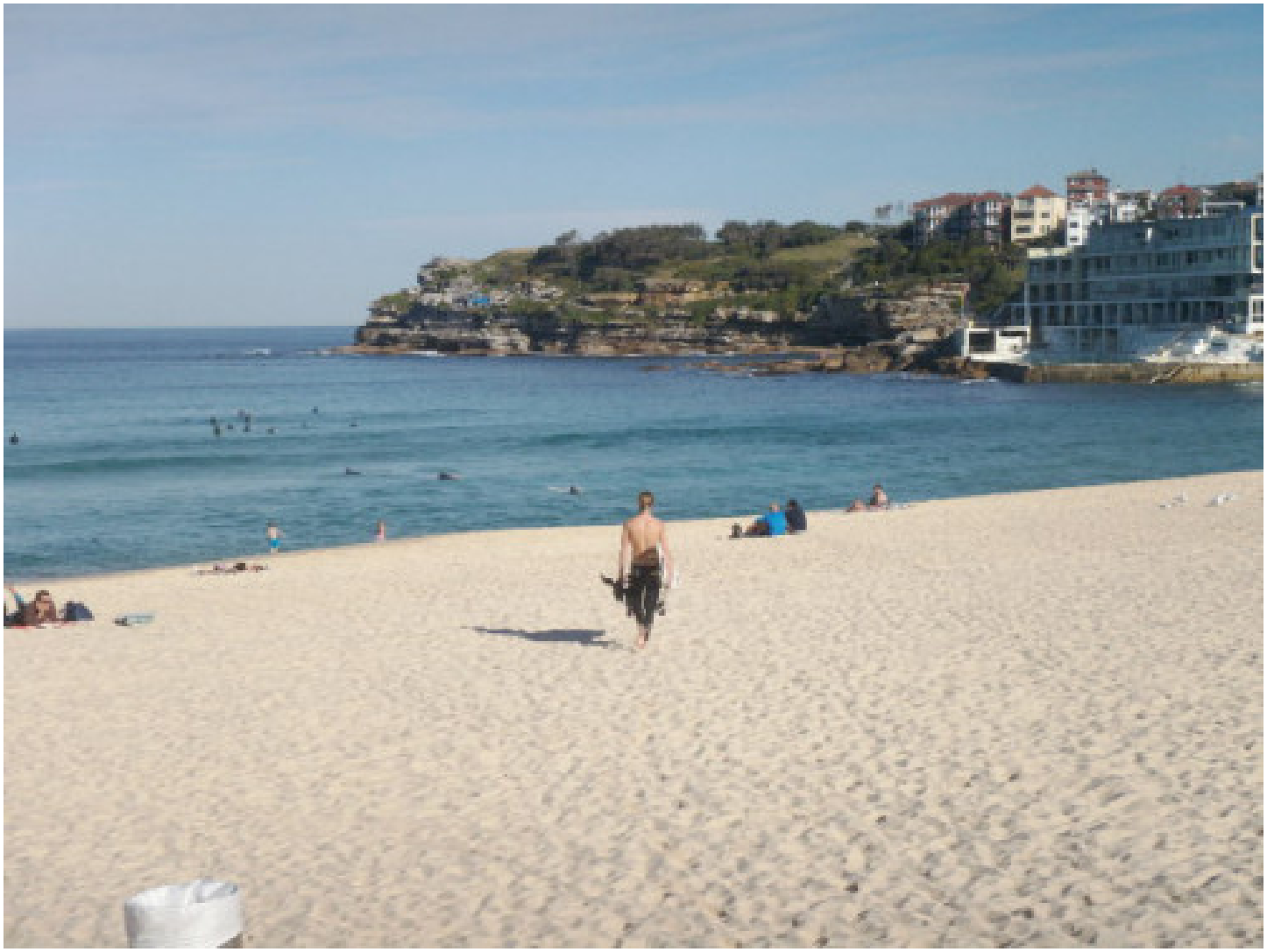
naïve but couldn?t we do away with the control arm, and just give everyone in the trial PrEP or diaphragms or condoms or whatever we?re testing and see what, if any, the natural rate of failure for that test might be? And if no one fails, and no HIV infections occur, wouldn?t we have gathered an answer without risking new infections?

With the conference over and my head spinning from reading so many posters and abstracts and listening to great scientists TRY to break down their nuanced and complex findings into lay person?s language, I tossed a few potato chips to the gulls and decided to check out famous Bondi Beach with Sean. Few places in the world look exactly like a postcard. Bondi, even in winter, is one of them. It?s a huge, yellow, sickle-shaped beach?a new moon of sand?curving from rock cliff to rock cliff. There are two breaks at Bondi?one that looked a little ride-able and the other an option only if surfing is your life. Black-rubber-encased bodies bobbed on the water; some sat, some lay, on their surfboards. Surfing seems all about the timing and somehow, though the incoming swells never looked different to me as they entered the mouth of the cove, the seal-like men and women read the surges of water with expert eyes, never wasting energy on dud waves, saving their exertions for the waves that rose up majestically, only to curl back on themselves like a closing centipede. We walked the length of the spectacular cliffs down to Clovelly. There are no barricades to the sheer drops of up to 80 feet into the clear blue water. We ended our stroll back at Bondi?s Swim Club where even in winter brave Aussies do laps in the unheated seawater-filled pool abutting the ocean. As swimmers crawled up and down the lanes at sunset, the waves broke over the pool?s stonewall adding a constant supply of fresh ice water that spilled out over the far end. We had cocktails high above the water daring each other to go for a dip. In the end, we decided our constitutions weren?t acclimatized. I was totally intimidated by the strong-backed girls doing pushups down on the exercise mat and couldn?t imagine how they?d snigger at my white, welterweight body. The people in Australia?both men and women?are oversized. Many are taller than six feet. In comparison, I would have looked like Olive Oil.

We went to bed watching ?Bra Boys? a movie about a special brotherhood of surfers who grew up on the point break at Maroubra (get it? ?bra boys?), south of Bondi. It?s a great film, narrated by Russell Crowe, and it gives an inside peak at those who take some of the greatest risks in surfing, traveling the world to face nearly un-surfable waves, even when they?re bleeding and even when the sharks are circling. I started my day feeling very courageous for having once faced the potential side effects of a drug I thought would be a good one for trying to save my life. I ended my day wondering whether I would seek ways to test my mortality if the reality of my mortality weren?t such an integral part of my every day. I envied the carefree nature of the Bra Boys. One of the best Bra Boy surfers?who faced jail time for allegedly obstructing justice in a local court case?used what could have been his last few weeks of freedom to fly around the world and rip down the face of a wave so big and deadly it is called ?Jaws.? It wasn?t that he wanted to die to avoid a possible prison sentence. It was that he wanted to be sure he?d lived as fully as he could in the event that he got locked up. I feel this sometimes, that I?d better do it now as there may not be a tomorrow. It?s a fine line between accepting that you have health and embracing the fragility of life. I just love the notion of not letting the uncertainty of tomorrow keep you home, worried, today. The spirit of pushing your boundaries to feel really alive is so important, especially for those of us who are often weighed down by the struggle to just get through the day. I?m not going

surfing anytime soon (I swim like a one legged duck). But I hope to find a way to get a little of that Aussie-devil-may-care-Bra-Boy-brotherhood-spirit into my life.

Pictures from Bondi...



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