



life beyond wheels

Person of the Year: Scott Rains



SCOTT



BUILDING BRIDGES

BY JOSIE BYZEK

Scott Rains' influence stretches across the globe. He's an enthusiastic advocate for all things tourism-related, whether it's a summons to KwaZulu Natal Province in South Africa to coach the government on how to unravel an adventurous trip to Glacier Bay, Alaska, to check out a new kayaking mother ship. Everywhere Rains visits, accessible travel options bob in his wake and universal design makes the transition from theory to reality. For all he does to ensure people with disabilities can boldly go where everyone else has gone before — and beyond — **NEW MOBILITY** is proud to name Scott Rains as our 2009 Person of the Year.



THE YEAR

RAINS



Photo by Eric Stampfli

Scott Rains kicked off 2009 by touring the DumaZulu Cultural Village in South Africa, where, to his delight, he witnessed a traditional Zulu dance. Pounding, staccato drum beats backed up an intensely masculine, athletic dance punctuated with guttural interjections. Sweat beaded on the men as they jabbed the air, and their bare feet slapped up swirls of fine dust. The performance lasted almost an hour as Rains watched, entranced.

Rains was pleased when, after the dance, he and others in the audience were encouraged to interact with the villagers. They felt included, part of the

group, learned to sing a bit in Zulu, and even got to wear traditional animal skin hats complete with tails. Rains especially loved the hat.

"If you run into one of those cool Zulu Daniel Boone hats," Rains told readers of his travel blog, *The Rolling Rains Report*, "send me one."

Rains wasn't visiting DumaZulu as a typical tourist. "I was there to see how accessible the village was," he says. Outside of the fine dirt that was hard to push through in spots, the village scored high.

"There were a few places I couldn't get through, but I actually could get around most of it," says Rains, 54, an incomplete quad who uses a manual chair.

"We visited DumaZulu because it is a typical stopping point for tourists," says Rains. "They do cultural demonstrations, but the people of the village are a living generation of Zulus who prefer that lifestyle. Like, our main interpreter, the business manager of the tour, was telling me about how he was negotiating for his seventh wife and got a deal since

usually a wife costs 13 cows and he only had to pay eight."

Polygamy aside, cultural villages like DumaZulu are comparable to Amish communities here in the states in at least one respect. These Zulu families, like the Amish, just prefer the traditional cultural values and technologies of the past.

Rains loves talking about the different peoples he meets when traveling, such as the Zulus, but he's quick to point out that he's not just there to sing and dance. What he's about is serious, big-bucks business.

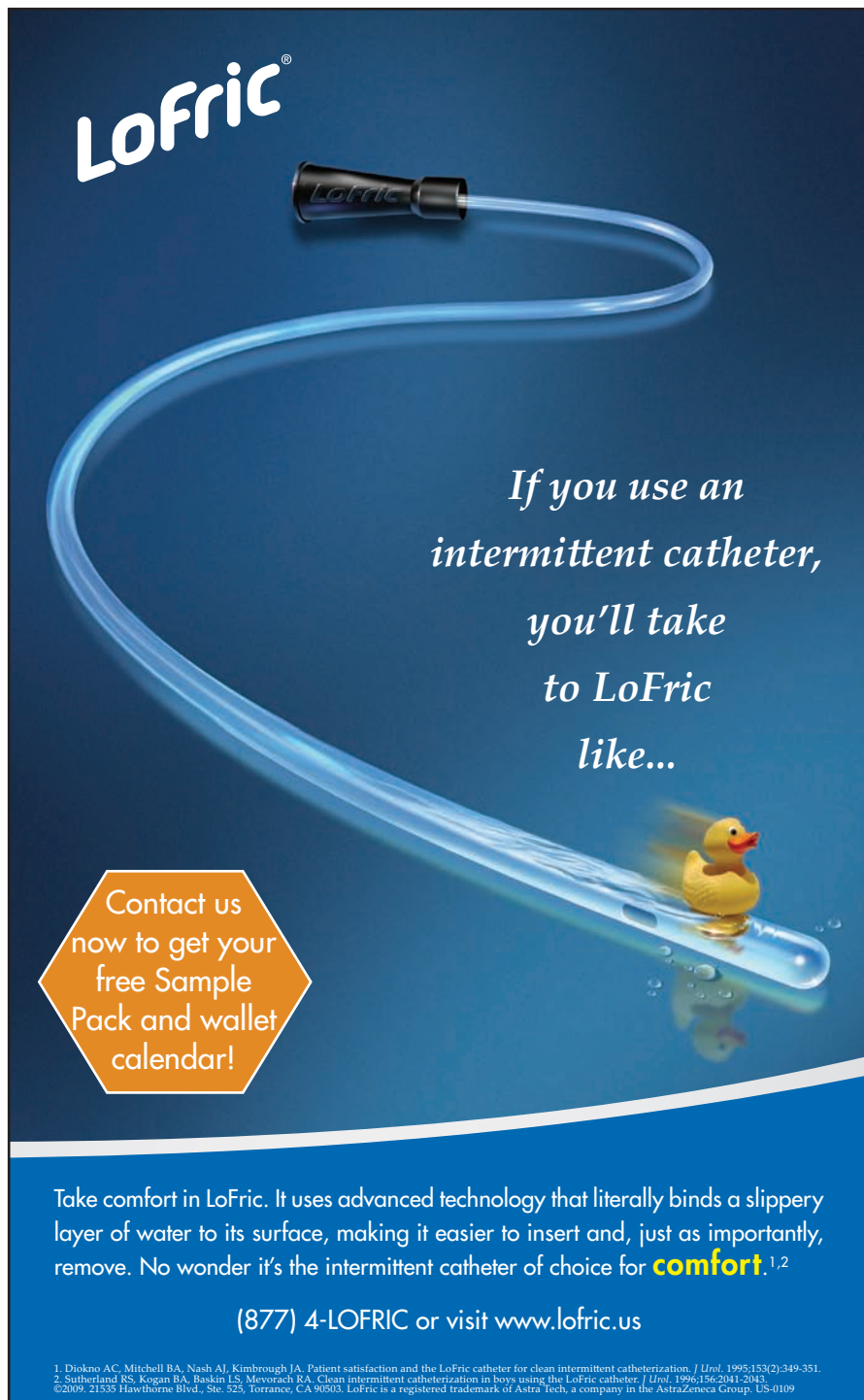
At the urging of Jennae Bezuidenhout, who runs Access 2 Africa Safaris, Rains decided to visit the Elephant Coast. "Jennae had contacts with the government, and the government was interested in having me come down in anticipation of the 2010 World Cup games, since accessibility is a government mandate as well as a mandate of the sport. I had heard that not everyone with their hands on the money was hiring people with disabilities to do the accessibility work, so there was some controversy." By "controversy" Rains, who prefers to be nonconfrontational whenever possible, means that he and others pushed

RAINS IS CONSTANTLY WEAVING TOGETHER DIVERSE STRANDS IN ORDER TO FOSTER A NEW 'WHOLE' WORLD THAT INCLUDES EVERYONE.

hard for access-done-right to be a priority, and who knows how to determine accessibility better than the people who need it? Hence, the push to hire South Africans with disabilities.

"Scott's visit created the opportunity to bring international focus to the important niche of tourism for people with physical disabilities, and it was a very successful marketing outreach for South Africa," says Bezuidenhout, whose husband, J.J., is a quad. "At the same time it highlighted, as encouraged by our country's constitution, South Africa's promotion of support and opportunities for the disabled."

Just about all nations but the United States are soccer enthusiasts, and the World Cup Games are like the Super



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2. Sutherland RS, Kogan BA, Baskin LS, Mevorach RA. Clean intermittent catheterization in boys using the LoFric catheter. *J Urol*. 1996;156:2041-2043.
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Bowl times a thousand, so this means a new airport will be built for the rural KwaZulu Natal Province, of which the Elephant Coast is a part. It also means more than 400 new or remodeled hotels and other places of lodging, plus restaurants, mass transit vehicles, and upgraded infrastructure for Durban, which is the area's largest city. With the whole world watching, KwaZulu wants to sparkle. And thanks in part to Rains, much of this shiny new infrastructure will be accessible.

What Rains does in situations like this is serve as a technical advisor and community organizer.

“When I get invited to a country, I’ll have a sponsor, generally a hotel chain or government, something like that,” says Rains. “If it’s my first time in the country or region, I’ll try to come early and stay longer. Between when I’m sure I’m going and when I get there, I start communicating with disability organizations. I find out who the disability leaders are in the area, tell them what I’m doing and invite them to participate. I put them in contact with the people who reach out at my level for expertise and point them to each other. I tell the businesses or government — ‘this is the local expertise you have, you guys should be working together.’”

For the disability community, this does a few things. First, it makes it possible for Americans with disabilities to have more tourism possibilities, and choosing to go to a relatively new hot-spot like the Elephant Coast is often much cheaper than, say, Paris. Second, it creates infrastructure that local people with disabilities can have access to long after tourist season is over.

It’s natural for Rains to take a small event, such as watching a cultural dance, and expand the experience to encourage access in a whole province that provides opportunities for disabled people worldwide. His trip created a vacation opportunity for disabled people in other nations, and also helped to create jobs for wheelchair users in KwaZulu Natal, as well as enabled an old-fashioned Zulu village to stay true to its heritage.

In technical terms, what Rains did in KwaZulu Natal was use inclusive tour-

ism (*travel for as many people as possible, regardless of ability level*) to bolster universal design (*ensuring that all new monies pouring into the province as a result of the World Cup go toward building infrastructure that can be utilized by both disabled and nondisabled people*), geotourism (*a style of travel that helps locals to keep the distinct flavor of a place authentically intact*) and world development (*money flowing from richer nations to poorer regions in ways that help all who live there*).

And Rains thinks like this all the time.

He’s constantly weaving together diverse strands in order to foster a new “whole” world that includes everyone.

A COLLECTOR OF TRAVEL EXPERIENCES

Rains’ love affair with travel began when he visited Guatemala as an exchange student while a sophomore in high school. “I realized that no one knew me, and I could reinvent myself,” says Rains. “I had a clean slate.” He went to Brazil his junior year to

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challenge himself further. "I was nondisabled, but I was vulnerable, at the mercy of other people, and I became aware of how you can evoke support just from the condition of being a traveler. So when I was paralyzed I had the courage to travel."

Rains had cancer when he was 13, and when he was 17 he sustained an incomplete injury at a high cervical level after a biopsy went wrong. He was spared some movement and sensation but still remains a quad functionally. "A lot of people think I was climbing mountains or something

like that and broke my neck, but nope. I just said they could get a piece of me and ended up not being able to walk."

Since he had already learned Spanish and Portuguese, and had a scholarship to study linguistics at Brazil's University of São Paulo, he decided, paralysis or not, he would keep traveling. He'd go back to Brazil, this time as a college student. He had already experienced the need to be interdependent with others, and this gave him confidence to try again.

But it wasn't that easy.

"I was around 21 by this time, and because it was cancer that led to my injury, I had questions about whether I was going to survive. There was a lot of pain involved, and odd pain as well that seemed to indicate things were worse than they were — it was an aggressive central nervous system cancer," Rains says. Plus the university wasn't very accessible, and Rains was new to all of this. He was only able to stay in Brazil for three months.

After Rains got the hang of international travel in a wheelchair, he returned to Brazil, and now it's his favorite place to visit. He says he has roots there, plus lots of friends. But then he goes on to say how Thailand is also his favorite, and also Argentina, and India, of course, and Korea's nice, too, and so it goes. They're all his favorite, and he enjoys collecting experiences.

Like his trip to Belize. His wife of 27 years, Patricia Narcisco, likes to tell the story of when they visited the Central American country. She starts by saying how much she respects her husband's independence and how he knows he can ask her for assistance any time he feels it's needed, but she always waits for his cue. "So we were ambling side-by-side down a rock-strewn dirt road, enjoying a warm tropical afternoon," she says, "when a local man approached us and, visibly outraged, pointed at me and said, 'Shove your brother, man.' Clearly in his view I had overlooked an important protocol. But Scott and I share a different ethic. What if my 'brother' didn't want to be shoved?"

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Scott Rains and his wife, Patricia Narcisco, were drawn together by a passion for social change.

Like her husband, Narcisco also shares a social consciousness. Currently she is director of development and marketing at Children's Discovery Museum in San Jose.

ARE YOU, LIKE, AN ANGEL?

"How I met Scott is a classic example of why he is so successful and has such an impact on inclusive tourism," says Sherri Blackstrom, owner of Waypoint Yacht Charter Services, based in Bellingham, Wash. She has a form of muscular dystrophy called Charcot-Marie-Tooth disease, and she loves to sail. "When I got into this industry, I looked for boats that had any level of access, and there really are not many. So I thought my business would be a small pay-it-forward venture. I did not know, expect or intend it to be what it is now, thank you, Scott Rains."

They met two years ago when Rains received a press release from Blackstrom about her business. "Because Scott is the techie he is, extremely computer savvy, he's set up to receive anything that comes out about accessible travel. He picked up my press release before I picked up my morning paper and called me on the phone. And that began the journey."

They talked about how it's too bad there aren't more accessible charter boats, how the field of inclusive tourism is beginning to grow, and how disability shouldn't be a barrier to travel. Next thing Blackstrom knows, she's trotting the world with Rains, giving presenta-

tions with him in faraway Italy and touring an accessible boat alongside him in closer-to-home Glacier Bay, Alaska.

"In Glacier Bay, Scott and I were comped trips on an all-inclusive accessible yacht that's a kayaking mother ship. One of the gals with us on the trip was a naturalist who said she's finishing her bachelor's degree in India, where Scott has spoken before. Immediately he shot off e-mails to his colleagues in India to give her connections," Blackstrom says. "He does things like this all the time. Within

a few days of that trip I said, 'Who are you really? Are you, like, an angel?' He's almost not human. He's on a mission." And yet he still takes the time to look out for the career of a young student.

Rains helped Blackstrom grow her business, and now 50 percent of all inquiries come from others with disabilities. And perhaps just as importantly from her perspective, he connected her to the first person she ever met who also has CMT. "Scott and I were working on a form with formatting issues that were driving

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us crazy, and he introduced me to Terri O'Hare, a graphic designer. Next thing you know we're chatting and she says, 'What do you have?' I tell her and she says, 'So do I!' And I had not known anyone with CMT on a personal level. I'm thinking to myself, Scott must have known this, but he said he didn't. Terri and I couldn't solve the formatting problem, but now we're friends," says Blackstrom. "Scott is just one of the most genuine and caring people I ever met in my life. I feel blessed to have met him, and my family feels the same way. To really gradually get to grasp the breadth of his mission and how he's choosing to live out his life, and to be included in that has left me speechless more than a few times."

O'Hare, owner of Albuquerque, N.M.-based O'Hare Communications, worked in the marketing department of an engineering firm for six years, saw what little regard architects and planners truly have for the ADA, and so is an advocate for universal design, which is how she's connected to Rains. "He takes his passion for travel and finds a way to make every issue about travel, universal design and access," says O'Hare. She first worked with him after Hurricane Katrina, when lots of funds flowed into the coastal area, but architects weren't taking accessibility very seriously. After advocates like Rains got involved, access planning improved, and O'Hare has been connected with Rains ever since.

O'Hare's style of advocacy is closer to ADAPT's. She's angry at urban planners, designers and architects who build people with disabilities out of their work, and doesn't hesitate to let them know. But she appreciates Rains' gentler approach. "I can't see Scott at an ADAPT rally, he's so Dr. Scott. My hot-headedness gets me in trouble. But I never catch him speaking ill of people, although I'm sure he could."

THE GOOD DR. SCOTT

Rains is always "on" when he talks to you, passionately explaining the details of inclusive travel, world development, geotourism and universal design. It's a whole lot of information, delivered gregariously. So it's a surprise to learn Rains, a quintessential extrovert, has a deep, contemplative side that draws its energy from Roman Catholic monasticism.

In fact, he holds a doctorate in ministry from Graduate Theological Foundation in South Bend, Ind., with a concentration on monastic study that he earned by scanning hundreds of copies of ancient texts dealing with the Benedictine tradition so scholars can study them online. "These documents missed the age of the printing press, and I wanted to make sure they didn't miss the digital age, too," says Rains, pleased to have played a part in saving those ancient voices from oblivion. "It's this impulse toward social justice, combined with my urge to wander, that allows me to focus in on certain things, like Sherri Blackstrom's yachts. I derive passion and joy from these actions, and that's wonderful. But on another level it's not about me at all. It's about the idea, the legacy, finding others sparked by the idea, getting in dialogue with them, finding out what's the kernel of truth here, and the sign of where the world could go that would be better," says Rains.

Rains is proud to be a Christian in the Roman Catholic tra-



Rains and a fellow advocate sit by the wall that marks the beginning of a no man's land between North and South Korea.

dition. "And I am also very comfortable, at home, in the Buddhist tradition," he says. "I really believe, and this is behind my compulsion to travel, that certain parts of the truth only become available to you in dialogue with other people, and if it doesn't respect the other person, it isn't dialogue — it's talking to yourself. And so I'm a humanist, and religion colored by humanism is a different kind of religion than one colored by certitude or fundamentalism."

WHAT IT MEANS

Geotourism: According to National Geographic, which coined the term, geotourism is defined as tourism that sustains or enhances the geographical character of a place – its environment, culture, aesthetics, heritage, and the well-being of its residents. www.nationalgeographic.com/travel/sustainable/about_geotourism.html

Inclusive Tourism: The goal of inclusive tourism is to accommodate the broadest range of tourists possible without stigma or the need for special accommodation. At its best, this means everyone travels together in the same vehicle to the same destination, where they enjoy the same activities, regardless of type of disability. For an in-depth article on inclusive tourism by Scott Rains, see www.suite101.com/article.cfm/travel_with_disabilities/114773.

Universal Design: The concept of universal design comprises seven principles that ideally lead to an environment filled with items that are easily accessed and used by the greatest number of people possible. This goes beyond the minimum accessibility requirements that we're all used to, via the ADA, and instead challenges a wide variety of fields and disciplines to begin including people of all ability levels into the original, intentional design. Scott Rains and others in the inclusive tourism field rely heavily on the principles of universal design to promote the idea that as many tourists as possible should have the exact same easy, flexible and intuitive access to a site as possible.

Read more about these design principles on the Center for Universal Design's website: www.design.ncsu.edu/cud/about_ud/udprinciples.htm.



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It's all about interdependence and vulnerability, in a sense, and all the ways we deeply need each other, says Rains. "I remember being 17, going through rehab. The emphasis was on independence, independence, independence. It makes sense, in terms of what we had to learn, but it's a distorted worldview. *Interdependence* is the core value that holds together the cultures of disability. When I travel and speak around the world, my lack of function shows us how dependent we all are on the actions of other people."

Perhaps it's this sense of connectedness and interdependence that allows a Zulu village to build in accessibility so that an American with quadriplegia can come visit. And maybe it's what allows that American quad to spend money in such a way that it helps to sustain that Zulu village's tradition and culture. It's all woven together, like Rains says.

The trick is to be mindful of the strands. Then to figure out how to stretch them in a way that co-creates our world. It's easy, suggests Rains. Just keep talking about it with each other and it'll all come together. MI

TRAVEL RESOURCES

Able to Travel, United Spinal Association, info@unitedspinal.org, www.abletotravel.org, www.unitedspinal.org; 718/803-3782. ABLE to Travel's agents can help travelers who use wheelchairs plan their whole trip.

Access 2 Africa Safaris, info@access2africasafaris.co.za or jennae@vodamail.co.za, www.access2africasafaris.co.za; 0027 35 5620614. This company specializes in accessible trips to the Elephant Coast of South Africa, including safaris.

Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers, Third Edition; barrierfreetravel.net. This \$20 book by Candy Harrington is a great resource for both new and veteran travelers with disabilities.

Epic Enabled, info@epic-enabled.com or admin@epic-enabled.com, www.epic-enabled.com; 27 (0)21 785 3176; skype ID epic-enabled. This company specializes in accessible trips throughout all of South Africa.

Emerging Horizons, www.emerginghorizons.com. This consumer-oriented magazine is all about accessible travel for people with mobility disabilities.

Rolling Rains Report, www.rollingrains.com. Scott Rains' blog focuses on all things related to inclusive travel and universal design from a variety of angles.

Society for Accessible Travel and Hospitality, www.sath.org; 212/447-7284. SATH is a nonprofit membership organization that works to raise awareness of the needs of all travelers with disabilities. **Waypoint Yacht Charter Services**, contact@waypointcharter.com, www.waypointcharter.com; 888/491-2949 or 360/656-5934. Waypoint specializes in customized boat trips to world-wide locales.

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Additional information is available at www.fscip.org regarding topics such as:

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- Liability, Compensation and Your Rights
- Getting Help: A Guide to Organizations
- Finding and Choosing an Attorney

Who You Need to Know

Ronald R. Gilbert began representing victims of spinal cord injuries and their families in 1981 and is one of the country's most experienced legal experts in spinal cord injury law.



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