

ABILITY

Kennedy Legacy

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and iCons**

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FROM MOVIES TO MOTORCYCLES



iCons in search of



Smith presents during a Demining Ceremony in Nicaragua

Globe-trotting William K. Smith, MD, founded the Center for International Rehabilitation, formerly known as Physicians Against Land Mines. The latter was co-recipient of a 1997 Nobel Peace Prize. These days, Smith also heads up iCons, an umbrella organization for a worldwide group of physicians linked to each other and to patients through the internet. Dr. Smith recently spoke with ABILITY's Chet Cooper, and Thomas Chappell, MD, the magazine's managing health editor.

Chet Cooper: We've met.

Dr. William K. Smith: At the UN, right?

Cooper: Yes, there and the World Bank— during their conference on disabilities. I think I met Eunice Kennedy as well that day.

Smith: There are a lot of people in my family running around. (laughter) A number of us work on disability issues. (Smith's mother, Jean Kennedy Smith, founded Very Special Arts, "to create a society where all people with disabilities learn through, participate in and enjoy the arts.")

Cooper: How did you get involved with iCons?

Smith: I have a cousin who lost a leg to osteosarcoma when he was fairly young. After completing my residency at Northwestern— I'm a physiatrist by training— I then trained as a prosthetist. After medical school, I spent time overseas with the International Medical Corps in Somalia, where I got a lot of exposure to people with land mine injuries. I became interested in amputee care and looked into it.

In 1996, I started Physicians Against Land Mines. Later, Princess Diana got involved and the issue picked up a lot of momentum for a while. We started the Center for International Rehabilitation in Chicago to work on mobility aids for those with land mine injuries, and other people with disabilities in conflict and post-conflict areas. Then, in '98, we started the first distance learning course on prosthetics in Latin America, working with clinics that served those wounded in war. Later, we expanded that program to the Balkans.

Dr. Thomas Chappell: You've also worked with Iraqi physicians?

Smith: This past year, we completed training for about 110 Iraqi health professionals, including physical therapists, hospital administrators and hospital-based physicians. Through the Iraqi Ministry of Health—funded by the World Bank—we engaged the University Clinical Center in Tuzla, our partner program in Bosnia. The Iraqis were flown there and received two to six weeks of training, which they took back to Iraq.

So I've been heavily involved in disability issues and training issues in conflict and post-conflict areas for about 12 years.

Cooper: You've used the internet in a very engaging way.

Smith: One of our board members, Ken Rutherford, is a land mine survivor. He did his PhD thesis on how the internet, as a low-cost tool to connect people, was crucial in the formation of the International Campaign to Ban Land Mines. This is rather remarkable because it really wasn't used nearly as much as 10 years ago. We rely on it extensively for education and training purposes now with our distance learning programs, and in our most recent initiative to connect doctors around clinical consultation.

This helps doctors in remote and/or medically underserved areas, such as post-conflict areas, where people tend to have poor access to specialty care. This could also be physicians on the Indian reservations in the U.S., or in inner-city areas that are underserved. So we're trying to connect many of the physicians.

Partner organizations such as the National Arab American Medical Association, the Iraqi Medical Science Association and the Chicago Medical Society are banding together to create a volunteer international workforce to help local physicians in Iraq, the Middle East and other countries deal with the huge humanitarian crises they face.

Cooper: You've done a lot.

Smith: I'll mention just briefly the other big initiative that we've worked on: The Convention on Disability Rights, which the United Nations recently passed into international law.

Cooper: It was actually your organization that was key in helping put together some of the Non-Governmental

Organization (NGO) meetings. I attended a few of them.

Smith: We were on the steering committee for the International Disability Caucus (IDC). We also pulled together the International Disability Rights Monitor, once again using the internet to help us. The monitor involves a research network of about 55 countries in Latin America, Asia and Europe, where we produce regional reports on disability rights. We give micro-grants to a country's researchers to produce the reports, and we train them how to write the reports.

That's all been under the UN standard rules for the equalization of opportunity for people with disabilities. As you know, that has now been eclipsed by the Convention, which has the force of international law. So we're in the process of updating our shadow monitoring and research methodology to reflect the protocols of the Convention.

Chappell: I'm interested in being a part of your Internet physicians' bank.

Cooper: Dr. Chappell is a neurosurgeon.

Smith: Let me give you an overview of how the program is organized, which may provide the information you need. In one scenario, a nonprofit organization that employs physicians becomes a member organization. Their physicians are authorized to practice medicine where they work, and they service a remote or underserved population. In addition to those in the service area or underserved population, any staff of the member organization can request assistance through the iCons program.

In another scenario, any three physicians can form a chapter and apply. They must be licensed to practice in the specialty that they represent, and be willing to provide three consults a year. Once you sign up with a chapter, you post your profile and get consult requests via email. Those requests contain a link. If you click on it, and decide you have the expertise to provide assistance,

the case comes out of the inbox. You then engage in one-on-one dialogue with the requesting person. That dialogue, which is encrypted to ensure maximum patient confidentiality, can continue as long as the two sides want. At the end, the case is closed.

We started with doctors, but intend to expand it to other health-related professions. We want to create a community of practice, as well as foster dialogue amongst interested professionals. We've been doing this as an NGO for years, whether it's been in the land mine area or the disability area, working with ad hoc networks or connecting peer to peer.

Chappell: How does the website work?

Smith: You go to the site and sign up as a general member. If you want to become a volunteer or a requester, you'll see the links. Click on those, fill out the necessary paperwork. It's not a heavy lift.

Chappell: Are there instructions about starting a chapter as well?

Smith: Yes. People can start chapters with any mission. They can say, "We want to focus on a particular area of medicine." Or, "we want to focus on a geographical area." They have total freedom to do that. Their profiles and the profile of their chapter are displayed on the site, so everyone can see who they are and what they're interested in.

Cooper: Have you looked into the digital divide in these remote portions of the countries you're working in?

Smith: We've been dealing with those issues for the last decade or so. The *New York Times* technology section did a piece on our original distance-learning program back in '97 or '98. About 50 percent of our initial class had never used a computer before. At that point, a lot of people said, "You can't do this on the internet; it doesn't exist in these places. People aren't going to have the skill set..." Interestingly, at Northwestern University, my



(l) Smith at a wheelchair clinic in Afghanistan; (c) with students in Bosnia; (r) holding a prosthetic

THE LEGACY CONTINUES

alma mater, the prosthetics school is now handled entirely via distance learning. I'd like to think our experience had something to do with that.

We've had success with the teacher/student/site-facilitator triad. We found that if we worked with clinics directly, and the site facilitator was invested in seeing this educational program work, they would make sure students had access to the internet. We found that many students actually used internet cafes and other means of access as well.

The growth of the infrastructure itself has been phenomenal. Most of the clinics are using email as an important means of communication. To that end, our software was designed to function at about the same bandwidth as standard dial-up (28k) email access. Remote requesters don't have to have broadband internet; they can have intermittent dial-up. To make a request, you click a button and it sends the request when it can get appropriate internet service.

Chappell: How much impact do you think that we can have as consultants? I've done informal internet consulting in recent years. With my particular specialization, I'm likely to recommend treatment that they're simply not going to be able to get. I've had friends who have actually gone places and built programs, helping out physically. They often bring older equipment that has been donated by hospitals, which have recently upgraded to newer equipment. Sometimes these can be high-level instruments such as CAT scanners. But often, in my specialty, volunteer physicians have to go back to methods used 20, 30, 40 years ago, for example, because they simply don't have the latest tools. So if I can't even be there to help them, even using older tools, how much impact could I have?

Smith: That's an important observation. It's interesting to watch the paradigm shift from traditional telemedicine, with point-to-point connections between a hospital here and a hospital there, to broadband with synchronous satellite-based streaming video and audio. Yet the connections with the most resonance still seem to be regional or local: The guy in rural Ethiopia who's looking for a solution to a problem may find a consultant in Addis Ababa, not Chicago. As you mentioned, there are cultural, geographic and economic issues, as well as other factors that will be better understood by people in similar environments dealing with similar concerns.

Sometimes people just don't know the resources that are available to them. In Nicaragua, for example, we found that there were people who were unaware of clinics that were within a 100-mile radius, and that dealt with the exact problems they had. If you're in the Army, let's say, you can email them about a kidney concern, and any one of a dozen renal specialists will respond. This kind of network is being expanded to NATO, and is proving to be the most durable form of telemedicine for

quite a range of specialties, anything from orthopedics to ophthalmology.

I would love to see people post profiles of practice environments, characterize where their own expertise is most useful and list repositories of equipment. All of these can become components of the program as a user base grows, and as the base expands, its real power emerges.

Cooper: How will it be funded?

Smith: It's remarkably inexpensive. We're currently funding it through grants and contracts we have with the Telemedicine Advanced Technology Research Center out of Fort Detrick, MD. We're also talking to internet technology companies, health providers and foundations. We hope national organizations within a country will be licensed to raise money independently, which can be used on the spot. We're about to establish national organizations in Bosnia, Jordan, Afghanistan and beyond. Surveys have been conducted in other Middle Eastern countries to identify groups that could take on the role of national organizations.

Chappell: I'm intrigued by this and by the prospect of becoming a consultant. Maybe I'll even start a chapter. I'm anxious to see how networking can be effective in terms of the intangibles you alluded to earlier.

Smith: There's definitely a learning curve. I think of it as being similar to a conference, in the sense that folks who are presenting are obviously central. Then there's the next ring of people who get up, ask questions and engage the speakers. Beyond that is a row of people who come to conferences fairly regularly, but don't speak up and engage. A row further back, you'll find people who wandered in, maybe this is their first conference. Your goal then becomes to move the outer groups closer in, one ring at a time. People have to get comfortable and familiar with the environment. As the inner circles begin to engage each other, the chance of success greatly improves. ■ ABILITY

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Smith with students at Don Bosco University in El Salvador

