



Our goal: For every child to be playful, happy, and healthy.

THE CASE FOR SUPPORT OF THE PONSETI INTERNATIONAL ASSOCIATION FOR THE ADVANCEMENT OF CLUBFOOT TREATMENT



An African schoolchild with untreated clubfoot disease

Each year, some 150,000 babies worldwide are born with congenital clubfoot, their feet so twisted that walking normally—or at all—will be impossible.

Untreated, the condition leaves people severely debilitated for life. And what has for years been the most common clubfoot treatment—a highly expensive and invasive series of surgeries—often does little to help: About 20 percent of clubfoot-surgery patients develop serious muscular and skeletal complications later in life, sometimes resulting in foot amputation, and up to 47 percent require further related surgeries.

The disorder's impact is felt most profoundly in the poorest regions of the world, where access to any medical treatment for the condition is rare. Eighty percent of cases occur in developing nations (about 1 in 500 newborns in Africa has clubfoot disease) where economic barriers lead to most cases going untreated. As a result, each decade more than a million children from developing nations are painfully disabled, unable to run and play and fully participate in the life of their communities.



Above and right: Dr. Ignacio Ponseti with patients and trainees

But thanks to expertise developed at The University of Iowa, hope is at hand for children around the world who suffer from this crippling disease:



“The Ponseti Method has become the ‘gold standard’ for treating clubfoot. . . . The development of educational programs for both healthcare personnel and the public at an international level has the potential to eradicate neglected clubfoot disorder, and dramatically improve the quality of life of all children born with this crippling deformity.”

John Sarwark, M.D., F.A.A.P.
Chair, Section on Orthopaedics
American Academy of Pediatrics

- A low-cost, low-tech, non-surgical clubfoot treatment—the Ponseti Method—exists, with rigorously documented full-correction rates of well above the 95th percentile. (In August 2006, the American Academy of Pediatrics endorsed the Ponseti Method as the “most successful, non-invasive, and cost-effective” clubfoot treatment and urged its use worldwide, including in developing countries.)
- Once properly taught, the Ponseti Method, named for Ignacio Ponseti, M.D., can be administered by health care providers such as nurses, orthopaedic officers, and physical therapists, making it an effective treatment for underdeveloped areas where there are few or no physicians.
- The University of Iowa established the **Ponseti International Association for the Advancement of Clubfoot Treatment** which, along with an advisory board comprising internationally distinguished orthopaedic specialists and other professionals, will serve as a centralized resource and catalyst for taking the Ponseti Method around the world, including to the most underdeveloped countries with high rates of clubfoot.
- The World Health Organization (WHO) stands ready to marshal its vast network to collaborate with the Ponseti International Association—in a unique partnership with the UI-based Global Public Health Campus (GPHC)—to organize the training and equipping of the nurses, physicians, orthopaedic officers, and other health care workers who will administer the Ponseti Method in the field.
- Unique information technology developed at the UI will enable regions without reliable Internet access—most of the world—to provide ongoing training in the Ponseti Method to successive generations, ensuring the long-term viability, continuity, and sustainability of this essential global public health initiative.
- Through careful tracking of clinical outcomes and the collection of genetic samples, UI researchers are working to unlock the genetic origins of clubfoot, which are currently not understood.

Thanks to an extraordinary interdisciplinary collaboration—among clinicians, researchers, information technology innovators, government agencies, non-governmental organizations, corporations, and others—the expertise and the organizational framework necessary to treat every child born with clubfoot, everywhere in the world, are in place.



Only one thing stands in the way of those affected babies being able to run, jump, play, and go to school with their peers: the significant financial resources necessary to implement the global Ponseti Method delivery plan.

To address this need and seize the present opportunity, The University of Iowa Foundation—on behalf of the UI Roy J. and Lucille A. Carver College of Medicine, the UI College of Public Health, and the Ponseti International Association for the Advancement of Clubfoot Treatment—has established a private fund-raising goal of \$100 million (including \$20 million to implement a global training and delivery plan) to successfully treat, on an ongoing basis, the majority of newborn clubfoot cases worldwide in 10 years.



“When parents are faced with this disaster of seeing a baby born with clubfeet, they get to be very depressed . . . But when they can see that this deformity is nothing, that is a very easy thing to correct and the child is normal, they have hope.”

Ignacio V. Ponseti, M.D.
Professor Emeritus
UI Department of Orthopaedics
and Rehabilitation

DR. IGNACIO PONSETI AND THE PONSETI METHOD

Ignacio Ponseti, M.D., professor emeritus of orthopaedics and rehabilitation in the UI Roy J. and Lucille A. Carver College of Medicine, came to the UI in 1941 as an orthopaedic resident. A medical graduate of the University of Barcelona, he treated wounded combatants during the Spanish Civil War before coming to Iowa. Now, more than six decades later—and well into his 90s—Ponseti still sees patients in the UI clinic.

As a young resident, Ponseti’s early work included outcomes research, in which he followed up on patients treated years before for a variety of orthopaedic problems. Among the conditions Ponseti studied was congenital idiopathic clubfoot, wherein (for reasons still unknown) the feet are turned inward and downward, making normal mobility impossible. Clubfoot is one of the most common birth defects worldwide.

Then, as is often still the case today, clubfoot had been treated primarily through invasive foot surgery, but results varied widely. Ponseti became convinced that there must be a better treatment for clubfoot than surgery. In the 1950s, he developed a non-invasive treatment—now commonly known as the Ponseti Method—that



“The Ponseti Method is based on a stretching of the ligaments and tendons, and then placing a cast in the correct position. If you start treatment with a newborn, with four to five casts changed every four to seven days, the foot is fully corrected when the patient is six weeks of age, and it will be corrected for the life of the patient.”

Jose Morcuende, M.D., Ph.D.
President, Ponseti International
Association for the Advancement of
Clubfoot Treatment;
Associate Professor, UI Department
of Orthopaedics and Rehabilitation

involves gentle, manual manipulation of the child’s foot and application of toe-to-groin plaster casts. The casts are changed every four to seven days after a clinician manipulates softened foot ligaments to gradually achieve normal muscle and bone alignment; the average treatment time is about 20 days. Following the succession of casts, a temporary simple foot brace is worn for decreasing amounts of time (only while sleeping), to keep the feet from turning back inward; after some months, the brace is never needed again.

The Ponseti Method has withstood the test of time. Ponseti and the UI are able to quote some 50 years of overwhelmingly positive follow-up results. In addition, peer-reviewed studies, in the United States and in countries such as France, Chile, Brazil, Malawi, Israel, Turkey, and India, demonstrate full corrections in more than 95 percent of clubfoot cases in which the Ponseti Method was applied, a remarkable rate for any medical treatment. And the material costs associated with the treatment—which with proper training can be done by nurses, physical therapists, midwives, and other health care workers as well as by physicians—are only about \$100 per patient, contrasted with thousands of dollars for surgeries. These material costs are for simple and easily obtained casting materials, such as plaster and cotton rolls, and the brace.

Experts recommend the adoption of the Ponseti Method on a global scale. In August 2006, the American Academy of Pediatrics endorsed the Ponseti Method, stating that “. . . development of educational programs for both health care personnel and the public at an international level has the potential to eradicate neglected clubfoot disorder, and dramatically improve the quality of life of all children born with this crippling deformity.”

Most important from a global public health standpoint, the treatment is simple (with proper training) and inexpensive to administer, making it greatly promising for children with clubfoot from developing regions of the world.

THE PONSETI INTERNATIONAL ASSOCIATION FOR THE ADVANCEMENT OF CLUBFOOT TREATMENT

To advance the Ponseti Method, the UI has established the Ponseti International Association for the Advancement of Clubfoot Treatment, with the mission of improving the treatment of children born with clubfoot, through education, research, and improved access to care.



The Ponseti Association is led by UI orthopaedic specialist Jose Morcuende, M.D., Ph.D., who has worked closely with Ponseti and traveled globally teaching the Ponseti Method. The association will take advantage of resources and interdisciplinary collaborations on the UI campus and around the world to—on a global scale—help restore normal function to children with clubfoot. These efforts will include:

- Educating physicians and other health care providers on the Ponseti Method through Web-based resources; scholarships for health care workers from underserved parts of the world to learn the method; and teaching programs in countries that have limited access to other sources
- Educating parents of children with clubfoot
- Helping provide better access to care, particularly in developing nations where medical materials are limited
- Basic research that advances the understanding of the underlying genetic basis of clubfoot and other musculoskeletal deformities impacting mobility, with the aim of finding better ways to prevent their development
- Clinical research that improves the evaluation and treatment of clubfoot and leads to current education and training of physicians and health care providers
- Partnerships to leverage maximum funding resources and foster collaborations with health care providers globally



Clubfoot children, after treatment with the Ponseti Method, participating in footraces on the UI campus.

The Ponseti Association’s work is aimed at developing the technological and training infrastructure to ensure that the Ponseti Method is accessible to every child born with clubfoot, everywhere in the world.

THE WORLD HEALTH ORGANIZATION AND THE GLOBAL PUBLIC HEALTH CAMPUS

As the United Nations’ health agency, the WHO has a vast international organizational structure in place—and in an extraordinary partnership, the WHO has committed to working with the UI and the Ponseti Association to eradicate clubfoot globally.

The WHO has declared the UI College of Public Health its inaugural collaborating center in an exciting new initiative: the **Global Public Health Campus (GPHC)**. Using software called *Elluminate Live!*, the GPHC allows experts from around the world to work together in educating and training health care workers, sharing research, and building a community of public-health workers. In real time, with even the most rudimentary of Internet connections, participants can talk, share documents, show slides, and collaborate. The GPHC currently has capacity for 150 simultaneous connections around the globe and this network can be expanded to connect an unlimited number of scholars worldwide.



Training local health care providers in developing nations (not just doctors, but also nurses, physical therapists, and other health workers) is a top priority of the WHO, and a key incentive to the WHO in working with the UI. Because the Ponseti Method—as a low-cost, low-tech procedure that can be successfully performed in remote, impoverished regions by health care workers at all levels—holds such promise, the WHO sees the Ponseti initiative as a blueprint for other global public health efforts involving hearing, vision, dentistry, and more.



Above and elsewhere on these pages: Ponseti Method training and patients in the field in Africa, Uruguay, China, and Japan.

Working through the WHO's global network of 6 regional offices, 150 country offices, and approximately 1,000 affiliated centers (such as universities, hospitals, public health departments, and clinics), the Ponseti Association envisions a 10-year plan, including travel to 10 to 15 countries per year for extensive hands-on training, with follow-up training occurring via the GPHC technologies. Underdeveloped African nations would be among the first to receive the training.

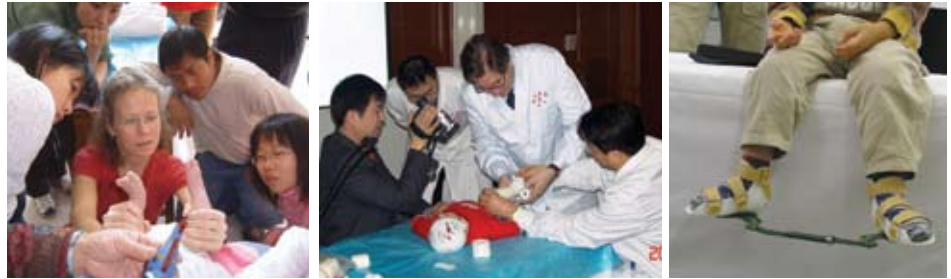
eGRANARY: STORING THE SEEDS OF KNOWLEDGE

A key element of the GPHC initiative is the **eGranary Digital Library**, a remarkable, inexpensive UI-developed technology.

Seven of every eight people on Earth lack reliable Internet access. In the world's poorest regions, simply maintaining electricity is a challenge, and if there are Internet connections at all, they are extremely slow. Just downloading a paper at a university or library can take hours, so utilizing the Web-based training videos produced by the Ponseti Association—which are crucial to ensuring the ongoing correct administration of the treatment—is out of the question under normal conditions in these areas.

Fortunately, the eGranary holds the key to ensuring ongoing, locally administered training of the Ponseti Method in remote locations.

The eGranary, already in use in scores of universities and libraries throughout Africa, puts millions of documents at the fingertips of those at educational institutions in



developing countries without using an Internet connection, by storing huge amounts of information on an inexpensive, transportable hard drive. The eGranary contains books, websites, journals, video, and audio files—including information on such practical and essential applications as digging wells, maintaining clean water, building roads, and other issues vital to healthy, sustainable communities. The content—which contains no advertising, pornography, chat rooms, blogs, or viruses—is provided by hundreds of contributing authors and publishers who freely contribute to help bridge the digital divide, as well as by the local users who determine for themselves what is important to make available.

Dubbed “the Internet in a box,” the eGranary will be an integral part of the Ponseti Association initiative in developing countries. Detailed, interactive training videos can easily be included in the eGranary, making possible ongoing, locally coordinated training programs.



THE LONG VIEW: DISCOVERING THE CAUSES OF CLUBFOOT

The final piece of the Ponseti initiative involves seeking the genetic cause of clubfoot. **Usually in the public health field, years of basic research comes first, followed by the development of clinical treatments based on the findings. In the case of clubfoot, however, the opposite is true.** The Ponseti Method is proven to be an effective treatment for the disorder, but congenital clubfoot is idiopathic, meaning the causes are not yet understood; the condition appears to be of genetic origin, and is thought to develop after the second trimester of pregnancy.

An essential endeavor of the Ponseti Association initiative is to facilitate the gathering of samples from the field and to create a clubfoot-disorder genetic database, working through the WHO/GPHC network. Medical and public-health experts from the UI Department of Orthopaedic Surgery; Department of Pediatrics; Department of Physiology; and Center for Bioinformatics and Computational Biology will lead the effort to unlock the genetic puzzle at the root of clubfoot and other musculoskeletal diseases that impact mobility.

HOW YOU CAN HELP

Congenital clubfoot is a crippling disorder affecting children worldwide—but it need not be. The Ponseti Method is an extraordinarily effective and low-cost treatment that can be successfully performed in remote locations by all levels of health care providers.

Partners and endorsing organizations:

- World Health Organization (WHO)
- Christian Blind Mission International
 - American Academy of Pediatrics
 - American Academy of Orthopaedic Surgeons
 - Pediatric Orthopaedic Society of North America
 - Bone and Joint Decade
 - CURE International
 - A Leg to Stand On
 - Operation Walk
- The World Computer Exchange

To realize the achievable vision of eradicating clubfoot around the world, the Ponseti International Association for the Advancement of Clubfoot Treatment will require significant (though in terms of global disease eradication, relatively modest) financial resources.

UI Foundation representatives can help you develop a gift plan that best meets your personal philanthropic and financial goals. Gifts to the Ponseti Association can be made outright, or in the form of pledges payable over several years. You can use cash, marketable stocks or mutual fund shares, or retirement plan assets; many forms of giving offer significant tax benefits. We would be eager to discuss appropriate recognition of your generosity, including potential naming opportunities and media publicity.

Your philanthropic investment in the initiative will in turn help the UI leverage additional funding and further essential partnerships with international and non-governmental organizations.

Most important, your gift to the UI Foundation benefiting the Ponseti International Association for the Advancement of Clubfoot Treatment will advance one of the most far-reaching global public health efforts ever launched, a disease-eradication project on a par with the worldwide effort to end polio or smallpox.



A happy Ponseti Method success story

For more information, please contact:

Christopher Collins

Director of Development, UI Carver College of Medicine
The University of Iowa Foundation
P.O. Box 4550
Iowa City, Iowa 52244-4550
(319) 335-3305 or (800) 648-6973

