

International Polio Victims Response Committee (IPVRC)

Mobility, Dignity, Integration

PROJECT : Treatment for 100 youth with disabilities in Congo

I. Summary of Project

The International Polio Victims Response Committee (IPVRC) is happy to have the opportunity to submit this project to Global Giving. Through this project, the organization aims to raise \$47,520 to use in providing a wide range of mobility-enhancing support for children and youth with disabilities in the Democratic Republic of Congo (referred to henceforth in this document as "DRC"). Specifically, this support will secure treatment in the form of leg braces, walking practice, physical therapy and (in some cases) surgery for 100 beneficiary youths. Without this support these youths would most likely never obtain access to treatment, remaining with only embarrassingly awkward and limited mobility throughout their lives. The improved, dignified mobility that will result from this effort will additionally bolster their self-esteem and allow them greater opportunity for social integration.

We hope to provide the following assistance through this project:

TYPE OF ASSISTANCE	DESCRIPTION	# OF PEOPLE ASSISTED	COST PER BENEFICIARY	TOTAL COST
Two badly damaged legs	Surgery, bracing and physical therapy for someone with two badly damaged legs.	5	\$2,090.00	\$10,450.00
One badly damaged leg	Surgery, bracing, and rehabilitation for one badly damaged leg.	15	\$990.00	\$14,850.00
Ankle deformities	Surgery and bracing for ankle deformities including "club foot" and deformity caused by leg paralysis.	20	\$770.00	\$15,400.00
Full-length leg brace	To receive one full-length leg brace.	20	\$165.00	\$3,300.00
Half-length leg brace	To receive one half-length leg brace (for ankle disorders).	20	\$88.00	\$1,760.00
Physical Therapy	For a beneficiary to receive needed physical therapy.	20	\$55.00	\$1,100.00
Brace-adapted shoes	For a beneficiary to receive a pair of brace-adapted shoes.	20	\$33.00	\$660.00
	TOTAL BENEFICIARIES ASSISTED:	100	TOTAL EXPENSES:	\$47,520.00

II. Problem Statement

Lack of access to needed services and equipment

Addressing the special needs of people with disabilities is a problem in many developing countries, but the situation in DRC is among the worst anywhere. DRC, a country of approximately 55 million people and geographically the size of the United States east of the Mississippi River, never achieved a high rate of polio vaccination and is one of the last bastions of wild poliovirus. Its population thus counts a disproportionate number of polio-affected disabled persons. In addition to polio, frequent meningitis epidemics and risky, ill-advised medical practices (such as injections of quinine to the hips to treat malaria) have added to the large numbers of people living with physical disabilities.

Africa, of course, presents special challenges for those who can't walk well or can't walk at all as a result of polio-caused paralysis or similar disabilities. Since streets are often unpaved, muddy, and full of people's rubbish, and as bathrooms are in many cases only primitive outhouses, just staying clean is a continual challenge for people who have to crawl or drag themselves along the ground to get around or who walk only with great difficulty.

In other countries, people suffering from lower-limb paralysis gain increased mobility by using canes in combination with orthopedic leg braces. In the DRC today, however, few individuals or families have the resources to pay for such equipment and thus never attain their maximum capabilities in terms of ease of walking and dignity. People in DRC are among the poorest in the world, according to several United Nations indexes, yet medical services are expensive and must be paid by each individual privately up front. This has led to an unprecedented lack of access to essential orthopedic equipment and services for those who need them. Furthermore, of the few people with disabilities that have managed to get some initial treatment, even fewer have the resources to return for essential, periodic follow-ups. Among the older adolescents with badly deformed limbs frequently seen around Kinshasa today, for example, many actually received braces or other walking aids as young children before the economic crisis set in, but were afterwards unable to replace outgrown or worn-out equipment so as to maintain their mobility and prevent deformities from worsening.

Though IPVRC has some funding from institutional sources to keep most of its brace-crafting shops and rehabilitation homes open for the next few years, the organization depends largely on individual donors to provide funds to purchase materials for brace-making and to finance surgery and plaster casting for those who require such treatment prior to bracing. The organization has recently launched a "sponsorship" program, whereby individual donors or donor groups can "sponsor" the treatment of a particular disabled Congolese youth, but this initiative is as yet too young and too little known to be able to handle the large number of back cases on the IPVRC waiting lists. Additional assistance is greatly needed.

Stigma

In addition to having virtually no place to go for affordable treatment, persons with disabilities in DRC face, like those in many other under-developed countries, a serious problem of stigma. The general population remains largely misinformed about the origins and nature of disabilities, and this results in general marginalization of the disabled or even ostracism. Some people in DRC avoid all contact with persons with disabilities for fear that they are dirty or that their affliction is somehow contagious. Others believe the disabled are "cursed" and that the physical disability is a supernatural "punishment" to the person or his/her family for some misdeed. Finally, many people simply prefer not to have contact with persons with disabilities so that they are never forced to ponder just how much more challenging life must

be for them. Generally, it is difficult for much of the Congolese population to avoid the tendency of viewing the disabled as "ruined" and incapable of contributing much to society.

Clearly, such attitudes on the part of the non-disabled often lead to discrimination and diminished opportunities for persons with disabilities in terms of education, employment, socio-economic integration and social participation. They also tend to have profound psychological repercussions for the disabled individuals themselves. In DRC, many become so self-conscious and lacking in self-esteem that they accept to live more or less on the fringe of society and associate only with other disabled persons.

III. About IPVRC

IPVRC is a U.S. registered, tax exempt, 501(c)3, not-for-profit charity created in 2000 to secure international financial support for selected community organizations in developing countries which:

- provide high-quality, locally-crafted leg braces (and accompanying necessary medical and rehabilitative treatment), at little or no cost to poor children and youth in developing countries paralyzed by polio or living with similar disabilities
- promote the full integration of disabled persons into society

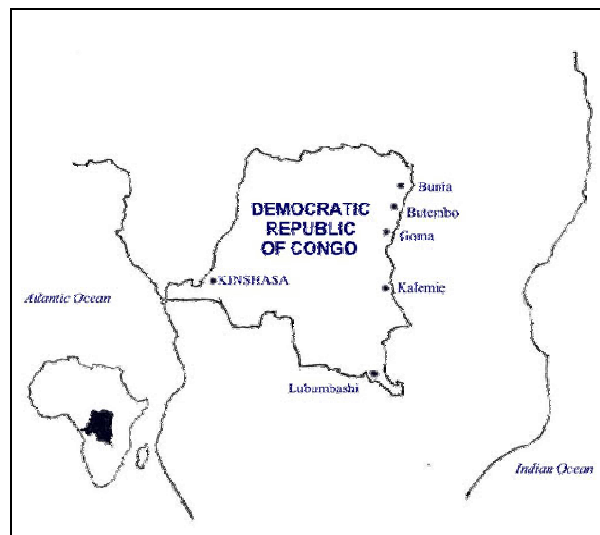
Underlying all of IPVRC's activities is a strong commitment to the beliefs that

- all physically disabled persons should have access to the orthopedic equipment they require in order to achieve maximum possible dignity, mobility and independence, and that
- a healthy society is one which permits and encourages the full integration of the physically disabled into all of its normal social and economic activities.

The organization's headquarters is in Loveland, Ohio, USA, on the outskirts of Cincinnati. It is governed by a 12-member Board of Directors, with input from a 6-member "Advisory Board" of persons prominent in the field of disability. The organization's revenue comes both from individual private donors and from institutions such as Pact Inc., the United States Agency for International Development, the Dikembe Mutombo Foundation, the Salie Foundation and the Liliane Fonds of the Netherlands. Most staff work on a volunteer basis and the organization is committed to keeping its "footprint" in the United States small so as to be better able to channel funds to programs directly benefiting youth with disabilities. Thus, the yearly percentage of revenue going to institutional overhead is consistently under 5%.

At the present time, IPVRC is concentrating its efforts on its program in DRC, where it works through an implementing local partner called ACAOJH (l'Association Congolaise pour l'Assistance Orthopédique aux Jeunes Handicapés, or "the Congolese Association for Orthopedic Assistance to Youth with Disabilities"). This Congolese-registered charity was founded in 1999 by a group of youth with disabilities specifically to address the problem of the lack of access of disabled persons to equipment that could make life much easier and fuller for them.

With IPVRC support, ACAOJH currently maintains brace-crafting facilities in six cities in DRC: Kinshasa, Lubumbashi, Kalemie, Goma, Butembo and Bunia. The outermost of these sites are located approximately 1000 miles from each other and correspond to the west, southeast and northeast corners of the country.



ACAOJH staff, who are responsible for the day-to-day running of the rehabilitation centers and brace shops, not only have key functions in project implementation, but also serve as powerful role models to new beneficiaries. Watching older disabled youths provide all the essential services and handle major responsibilities provides a profound boost to newcomers' confidence and tends to both foster a positive attitude toward life and help them see the future as having limitless possibilities.

IPVRC and ACAOJH are jointly dedicated to responding to the treatment and equipment needs for as many children with disabilities in the country as possible, knowing that increased mobility usually leads to increased dignity, integration, and opportunity. Recognizing, however, the importance of full social integration of persons with disabilities starting at an early age, IPVRC and ACAOJH supplement their primary brace-provision activities with an education program in which parents of disabled children are given some assistance in sending them to regular neighborhood schools with normal curricula (as opposed to segregated schools for the disabled with special, limited vocational curricula) where they can study alongside children who are not disabled.

This educational supplement to the brace program combats destructive stereotypes in the society by giving teachers, school administrators, parents, other children and the disabled children themselves ample opportunity to observe that in most activities, children with disabilities are no different from anyone else. Since it gives children with disabilities equal opportunity to develop their intellectual and social capacities, it is also contributing to bringing down stereotypes on a wider scale by assuring that in DRC's future there will be a relatively visible pool of well-educated persons with disabilities exercising constructive roles in the workforce and in the society in general. ACAOJH beneficiaries are ambitious. Many want to grow up to be doctors or lawyers. Prior to entering the program, however, their aspirations were limited, as is the usual case for disabled persons in DRC, to attending a "special" school where they would learn a trade like book lamination, tailoring, shoe-repair, artifact crafting, etc.

IV. Additional information regarding medical services provided, methods and approach

In general, IPVRC/ACAOJH's beneficiaries belong to one of two subcategories:

- "simple cases," whose paralyzed legs are still straight enough to be fitted with braces directly, and
- "complex cases" who require some initial surgery and/or plaster casting or other treatment before being ready for bracing

For simple cases, ACAOJH simply crafts the necessary equipment then provides post-delivery rehabilitative services (including extensive walking practice).

In complex cases, IPVRC/ACAOJH first finances surgery or other treatment under the care of a qualified, licensed Congolese health practitioner (usually at a local center for the disabled or at a hospital), then brings the beneficiary to the ACAOJH center for the fitting of braces when the initial treatment is completed.

About braces

Though being able to stand and walk with braces and crutches is by no means a solution to the problem of how to make a living in an underdeveloped country like DRC, it unquestionably helps "level the playing field" in the general competition for survival, and, most importantly, usually has an enormous positive effect on both the disabled person's own self-esteem and on the degree of respect granted him or her by others in the society.

Leg braces do not actually "hold" a person up, but rather serve to keep certain weak joints straight so that the wearer's own bone structure supports his or her weight. They also help to keep legs and feet in "correct" positions, preventing the development of, or return of, muscle contractures or other deformities.

In countries where plastic is readily available, braces can now often be made to hug closely a person's legs and slip inside shoes, offering lighter weight and greater concealment. Since securing the supplies and equipment necessary for making and replacing plastic braces is still extremely difficult in DRC, and since braces there typically get very hard use and thus need to be particularly tough, ACAOJH offers instead durable, high-quality hinged metal braces fitted to second-hand imported shoes. Though to the lay eye these may appear "heavy," a full leg brace weighs only about 4 lbs., and a below-the-knee brace only about 1.5 lbs. Few wearers complain of excess weight, and many who have tried both metal and plastic types, in fact, say they feel more secure in metal braces than in the less strong and less durable plastic type.

Why braces rather than wheelchairs?

Since wheelchairs and tricycles do not require any surgical interventions or customized equipment, this question often arises. In DRC, IPVRC and ACAOJH have adopted specifically a "bracing" response to the mobility needs of disabled persons for several contextual reasons:

- Unlike most contemporary paralysis cases in the developed world (which result now mainly from spinal cord injury rather than polio, meningitis, or bad injections), Congolese who are suffering from leg paralysis do not usually need to be in wheelchairs, since their backs and arms are usually strong. Wheelchairs would not be a particularly useful solution in most parts of DRC anyway, even if the disabled had access to them and a way to maintain them, since few buildings have wheelchair ramps and since the streets are so often of sand or mud.

- Though with its greater power and stability, a specially-adapted, hand-driven "tricycle" can be a very practical aid for a disabled person in long-distance displacements even in the difficult conditions of DRC, tricycles also have some significant drawbacks:
 - they do not help much in addressing the "stigma" and "self-esteem" problems. (In DRC, disabled persons who are seated in tricycles do not receive much more respect from the general population than those who are still simply on the ground. Those, however, who have given up tricycles in favor of getting around on braces and crutches typically report a huge improvement in the degree to which they are accepted by the rest of society.)
 - they are too big to go into most public establishments, meaning users must still get off the tricycle and crawl inside on the floor. (Most tricycle users don't even try to go into stores or restaurants, due to the risk of causing an embarrassing spectacle and/or being rejected at the door.)
 - they frequently break down, and breakdowns often occur when the user is far from home and has no other way to get home. Tricycles are too big to fit in a car for transport to a repair shop, spare parts for them are hard to come by, and users often cannot afford the repairs in the end anyway. (In the homes of a great many disabled Congolese now crawling around on all fours can be found, abandoned in some corner of their houses, the rusting remains of a long-broken-down tricycle that was the gift of some philanthropic institution at some point but which turned out to be beyond the person's means to repair and maintain.)

Though IPVRC and ACAOJH respect fully the choice of people who, for one reason or another, have opted for wheelchairs or tricycles over bracing, the organizations feel that their specific goals, the broadest and most long-lasting impact, particularly in such realms as promoting integration, boosting beneficiaries' self-esteem and confidence, and obtaining greater societal respect for disabled persons, can be achieved by concentrating on the provision of braces. Other providers are, in any case, available for these other types of assistance.

Rehabilitation

With IPVRC funding, ACAOJH maintains "rehabilitation homes" at all six brace-crafting sites to give new beneficiaries a place to stay while they are getting accustomed to walking with their new equipment and undergoing physical therapy (for those requiring it). Staff accompanies new brace-wearers through a number of walking exercises every day, and trained physical therapists provided specialized rehabilitation services at regular intervals. As ACAOJH staff are mostly themselves disabled and wearing braces, they relate easily to the initial difficulties of the beneficiaries they are helping and are particularly well-suited to provide the right mix of firmness, persistence and encouragement.

ACAOJH tries to keep new beneficiaries at the rehabilitation home until it is clear that the beneficiary not only walks well with the equipment, but has gone beyond "accustomization" to reach the point of seeing clearly its added value and "liking" wearing it (usually clear from the extent to which the beneficiary hurries to put on a brace in the morning and does not seek opportunities to remove it during the day). Only then can ACAOJH staff feel relatively sure that brace-wearing will continue when the beneficiary returns to his/her home, particularly in the case of younger beneficiaries. Parents in DRC are often not home during the day to provide close supervision, so a lot of responsibility falls directly to the beneficiary.

But "rehabilitation" at an IPVRC/ACAOJH facility is meant to be much more than simply mastering the physical aspects of brace wearing. Aware that effective treatment for physically disabled persons often also

includes extensive follow-up, peer support, confidence building, and attention to special psychological needs, ACAOJH provides beneficiaries with highly individualized care and treats beneficiaries more as members of an ongoing association of mutual support—members of an extended family of friends facing similar special challenges—than as simply outpatients at a medical clinic. Staff thus employ a uniquely personal approach—tailoring rehabilitation regimes to the personality of each beneficiary, being willing to let each progress at his/her own speed, and taking the time to find for each case the most effective blend of coaxing, pressure and patience.

In their more candid moments, virtually all disabled youth in DRC will admit to having frequent experiences of having people stare at them, laugh at them, pity them, mock them, or consistently underestimate their physical and mental capacities. Unsurprisingly, this can deeply damage self-confidence and self-esteem. Stays at the ACAOJH rehabilitation homes, however, can remedy much of this damage. Surrounded by older, well-adjusted, highly positive staff who are also disabled—who just through their daily work illustrate quite concretely how disabled people can play useful roles in society—young impressionable beneficiaries pick up the message that they should not feel particularly limited and that they should not worry too much about how other people react to them. At the rehabilitation home, new beneficiaries are also surrounded by a specially-selected resident core group of peer mentors—youth with a particularly positive attitude toward life who have a demonstrated ability to infect others with enthusiasm, pride and self-confidence, and who dispel self-consciousness by their willingness to dance, play soccer and go out in public wearing shorts (with their braces fully exposed to public view). As a consequence of this extremely supportive and empowering environment, rehabilitation home staff frequently observe fairly dramatic changes in beneficiaries attitudes towards themselves and their disabilities in relatively short periods of time.

Follow up

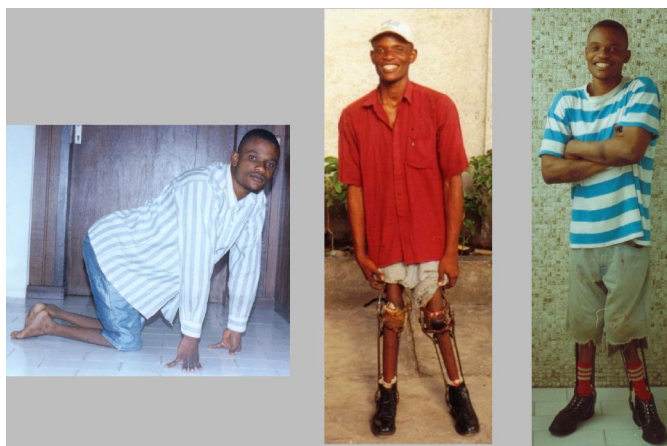
During new beneficiaries' stays at the rehabilitation homes, ACAOJH staff work to establish a relationship with them strong enough to ensure that the beneficiaries will return regularly to the home facility for visits after going back home to live with their families. Thus all former beneficiaries leave secure in the knowledge that they are welcome to return to the home to spend a few days there without question whenever they need to. While these visits are important to staff in terms of being able to monitor a beneficiary's progress and the condition and continued appropriateness of his/her braces, it is clear that they also provide beneficiaries an opportunity to enjoy once again the highly supportive environment at the rehabilitation home and get a "recharge" of self-confidence and courage to deal with the non-disabled world outside.

IPVRC/ACAOJH provides free repair—including the replacement of worn shoes—to all former beneficiaries. Whatever other special challenges beneficiaries face surviving in the non-disabled world outside the walls of the rehabilitation home, IPVRC and ACAOJH want them to at least be rest-assured that their special needs in terms of mobility and dignity-enhancing orthopedic equipment are covered—that IPVRC/ACAOJH will continue trying to keep the "playing field" as level for them as possible.

There is also a formal follow-up effort. For younger beneficiaries, if they do not visit the rehabilitation home or the brace shop in 6-8 months, ACAOJH will send a staff member to their homes to ensure that they continue to wear essential equipment, that the equipment still fits properly, and that they have not become withdrawn socially or developed negative attitudes about themselves. In cases where visiting staff feels that there has been slippage either in equipment use or psychological well-being, they will recommend a brief return stay at the rehabilitation home to a child's parents.

V. Impact: Statements from some current and former beneficiaries

A) From Didier Bofatshi, age 27: *"Though I had received braces and crutches at age four when I first got polio, by 1992 they had become too short and I was reduced to getting around on all fours. I stayed this way for 9 years because we didn't have money to buy new canes and braces. It was very difficult and painful. By the time I reached the fourth year of secondary school I no longer wanted to go to school because it was so difficult for me to get there, especially when it had rained and the streets were all mud or when the sun was shining brightly making the ground extremely hot. ACAOJH paid for me to travel to Kinshasa...where I had to undergo an operation to re-straighten my legs, which had become bent through non-use. After the operation, I received the braces and crutches I had waited for during 9 years of suffering. Once again on my feet and walking upright, I began to realize that I could be useful to society. At first I was not anxious to return to school, but ACAOJH staff convinced me to give it a try and paid for my studies. Now I have successfully graduated from secondary school and am very happy. I am confident of my abilities, and proud of my accomplishments. I am now myself working for IPVRC/ACAOJH. I have stayed on because I didn't know that someone like me could become what I am today and want to help other youth with disabilities."*



B) From John Kadiwaku, age 23: *"I came to ACAOJH when I was 19. Prior to this, I had been crawling on all fours for fourteen years, not having the financial resources to get any treatment. ACAOJH took me in, paid for my operations, my braces and my schooling. The affect on my life has been significant: people now see that I can be of value in the society – even those who didn't consider me worth much before. This effort must continue so that all persons living with disabilities can benefit."*



C) From Mashila Mulemba, age 21: *"Before I couldn't walk. This went on for a long, long time. I went to school anyway, on my hands and knees. It hurt me to see that other disabled persons could get around on crutches and braces while in my family we didn't have the money to obtain these. Finally, someone told me that there was an organization that was providing such equipment, and operations, for free. Now I can stand and walk with my two crutches and braces. The happiness this has brought surpasses anything else in my life. Now I'm in my final year of secondary school studying electronics. Whereas I used to have to stay seated even during lab sessions, now I can stand at the table with the others. Before I never attempted to dance, but now I enjoy dancing. I even play soccer, albeit using canes and braces. Being able to stand has also enabled me to become a successful barber in my spare time. I hope that IPVRC and ACAOJH can go on to help many other disabled youths."*



D) From Sarah Maseyi (left below), age 15: *"I am very happy to see what level I've reached now. Before I couldn't walk, now I can. I can go to school, do all kinds of work, and even dance."*

E) From Sylvie Matondo (right below), age 16: *"Now I am very happy. I couldn't walk before, now I can not only walk but also attend school, which is what I always wanted. I am very thankful."*

