The Case for Investing in Clubfoot Treatment
The Case for Investing in Clubfoot Treatment

A Problem We Can Solve

Understanding Clubfoot

Clubfoot is one of the most common birth defects and a major cause of physical disability globally. The vast majority of cases are diagnosed at birth and occur in otherwise healthy babies. Clubfoot is easily identifiable by the way the feet face inward and upward. Left untreated, this disability makes walking extremely difficult and painful. However, the position of their feet is the only medical obstacle preventing most children with clubfoot from living fully functional, productive lives.

There are 9.8 million people alive today who were born with clubfoot, of those 7.8 million live with disability due to lack of access to proper treatment. Every year, an estimated 200,000 children are born with clubfoot globally, or 1 in 800, but this rate is likely underestimated. With proper treatment, more than 95% of babies born with idiopathic clubfoot can achieve full correction and mobility. Without treatment, children live with a severe impairment and endure a lifetime of negative health, social, and economic consequences.

Clubfoot is correctable with the Ponseti method—a highly effective, low-cost, innovative medical intervention that results in complete correction of clubfoot and full functionality in nearly all cases. Treatment involves a series of weekly casts to gently reposition the feet and a simple outpatient procedure to release the Achilles tendon, followed by use of a foot abduction brace, worn for 4–5 years while sleeping to maintain the correction and reduce the chance of relapse. When initiated during infancy, the position of the foot is usually corrected within six to eight weeks.

associated with surgery mounted\textsuperscript{5,10,11} and countries around the world embraced the Ponseti method as the standard of care.\textsuperscript{30}

Since then, researchers have continued to document the method’s excellent short- and long-term outcomes in low- and high-income countries alike.\textsuperscript{5,11-13}

A variety of healthcare professionals, such as physical therapists and casting technicians, can be easily trained to provide the treatment. The method does not require general anesthesia or surgical capacity, involves only basic medical materials, costs about $500 USD per child, and achieves superior long-term results compared to surgery.\textsuperscript{11,14}

9.8 million
people alive today were born with clubfoot.

7.8 million
never received proper treatment.
A Childhood Correction Leads to a Lifetime of Benefits

Navigating life with a disability in countries with limited infrastructure and social support can be exceptionally difficult.

For caregivers and families, disability takes an economic and social toll.

In a recent study, mothers in low- and middle-income countries (LMICs) perceived having a disabled child as worse than death.\(^{16}\) The burden of caregiving for people with disabilities in LMICs has been mostly neglected—including the physical, financial, social, and emotional consequences.\(^{16}\) The responsibility of caring for children with disabilities, like untreated clubfoot, falls predominantly on women and mothers.\(^{16}\) Caretakers in many contexts suffer from discrimination and stigma—including mothers who may be blamed for giving birth to a child with a birth defect or disability—while entire families are often negatively affected by stigma and diminished opportunities for education, jobs, and participation in community life.

For people living with disabilities, the consequences can be far worse.

Compared to children without disabilities, children with physical or developmental impairments are 49% more likely to never attend school, 42% less likely to have foundational reading and math skills, 41% more likely to feel discriminated against, and 51% more likely to feel unhappy.\(^{17}\) In addition to the enormous health and social consequences children with disabilities face, they also bear direct and indirect financial costs. People living with disabilities and their families spend significantly more of their income on healthcare, assistive devices, transportation, and other services just to achieve the same or similar standard of living as individuals without disabilities.\(^{18}\) They are also 50 times more likely to acquire catastrophic healthcare costs.\(^{19}\) Finally, 80-90% of people with disabilities of working age in low-income countries are under or unemployed.\(^{18}\)

When children born with clubfoot benefit from high-quality treatment, they avoid all of this. With effective treatment, many barriers for a healthy and productive life fall away, such as the stigma of disability and mobility challenges, allowing children to fully participate in their communities and to thrive. Children who are treated will also earn an estimated average of $120,000 more over the course of their lifetimes than they would living with a severe disability—a 240 to 1 return on the initial investment of $500 spent on clubfoot treatment within the first year of birth.\(^{20}\)
By investing in the healthcare and assistive technology needs of children with disabilities, philanthropists, donors, non-governmental organizations, and countries not only improve individual lives, but they also unleash global economic potential and build the long-term capacity of healthcare systems. **If treated, the $120,000 lifetime return on investment applied to approximately 200,000 children born with clubfoot in LMICs each year equates to $24 billion in additional earnings added to world economies over the course of their lives.** Prioritizing clubfoot treatment also expands and strengthens the health workforce. Investing in physical therapists, orthopedic surgeons, and nurses—the staff needed to treat clubfoot—contributes to the same medical systems that help children and adults with other musculoskeletal and physical difficulties. Treating each case of clubfoot has enormous personal and global benefits.

**Clubfoot Intervention Benefits:**

- $500 invested per child leads to a lifetime of opportunity and financial return.
- **ROI of 240X, approximately $120,000.**
- 97% of parents say their child’s quality of life has improved because of clubfoot treatment.
Global Health Investment Has Proven Benefits

In the last 20 years, global donors have invested a collective $103 billion in development assistance dollars (2019 USD) to save and improve the lives of children around the world—and enormous progress has been made. As a result, the mortality rate for children under five dropped by half from 78.3 deaths per 1,000 in 1999 to 37.7 in 2019.\(^{21}\) The combined efforts of philanthropists, governments, and health systems can make incredible progress possible, especially with pooled resources and coordinated attention toward achievable goals. Since the 1980s, illness and fatality related to guinea worm, leprosy, polio, and HIV have decreased significantly around the world as a result of global health community action—and funding.

Unbeknownst to many, external congenital anomalies, of which clubfoot is one of the most common and serious, cause more health loss (defined as death, illness, or disability) in children than any infectious or parasitic disease combined—conditions you hear about far more often, like malaria and HIV/AIDS.\(^ {22}\)

Due to global birth rates, 90% of new clubfoot cases occur in LMICs where treatment is unavailable or very limited.

90% of children born with clubfoot live in LMICs

\(200,000\) new cases per year by country and GDP per capita

- = low- and middle-income countries
- = high-income countries

Sources: \(\text{Mol, et al.}, \text{Smyth, et al.}\)

\n
GDP per capita

Source: The World Bank
Each of the following conditions share some aspect in common with clubfoot—disability, stigma, treatability, or prevalence—and their respective investments have led to striking progress:

**Guinea worm:**
Like clubfoot, guinea worm can lead to preventable pain and disability. In 1986, the International Campaign to Eradicate Guinea Worm began. Since that time, an estimated $432 million (USD) has been invested in the effort and cases have decreased by 99.99%, from an estimated 3.5 million cases in 1986 to 27 reported cases in 2020, virtually eradicating the disease.

**Polio:**
Clubfoot and Polio can both cause devastating but preventable lifelong lower limb disabilities that diminish mobility in children. The world has galvanized attention and coordinated resources to eradicate Polio. Public and private donors have invested more than $16 billion USD since 1988 to eradicate polio, and the public health outcomes have been tremendous. In 1988, there were about 350,000 cases of polio in 125 countries; in 2019, 175 cases were reported.

What do Polio and Clubfoot have in common?
More than you think.

A polio resurgence would affect as many children as clubfoot does every year, according to the Gates Foundation.

Polio spurred modern physical rehabilitation and orthopedic innovations that improved quality of life and mobility for millions living with disabilities.

Treating clubfoot in LMICs began with pediatric orthopedic surgeons working in Uganda to reach children with severe polio disabilities. Overwhelmed by thousands of people living with neglected clubfoot who came to their surgical campaigns, they pioneered the nonsurgical Ponseti method in Uganda. Eventually their work proved the Ponseti method could be done extremely effectively in low-resource settings, contributing heavily to the global movement to end clubfoot disability in LMICs.
**HIV:**

More children are living today with untreated clubfoot than with HIV. Pediatric HIV infections and clubfoot affect similar numbers of newborns annually. However, since 2010, donors have spent more than $104 billion (2019 USD) to prevent and treat HIV and AIDS. As a result, more than 26 million people are now accessing antiretroviral therapy, and since 2010, new pediatric HIV infections have plummeted 52% from 310,000 to 150,000 per year in 2019.²⁵

**Leprosy:**

Today, there are approximately 100,000 new cases of leprosy annually,³ half the incidence of clubfoot—and down from 5 million in the 1980s. Left untreated, clubfoot and leprosy are both disabling conditions that lead to devastating physical disability, social isolation, and lifelong economic consequences. Thanks to effective multi-drug therapy (MDT), the reported prevalence of leprosy decreased 99% over the past 30 years. Since 1981, 16 million people have received MDT as a result of over $100 million invested since 2000.

There is abundant evidence that prioritizing and funding global health disease and disability leads to individual as well as societal benefits. Donors, multilateral organizations, and recipient countries have an enormous untapped opportunity to expand access to clubfoot treatment that could prevent nearly all lifelong disability caused by clubfoot for future generations as well as for the more than one million children living with clubfoot today.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number of new cases in 2020</th>
<th>Number of new cases per year</th>
<th>Estimated Institutional Global Investment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guinea Worm</td>
<td>27</td>
<td>3.5 million (1986)</td>
<td>$432+ million (since 1986)</td>
</tr>
<tr>
<td>Polio</td>
<td>175 in 2 countries</td>
<td>368,233 (1988)</td>
<td>$16 billion (since 1988)</td>
</tr>
<tr>
<td>Pediatric HIV</td>
<td>150,000</td>
<td>310,000 (2010)</td>
<td>$104 billion (since 2010)</td>
</tr>
<tr>
<td>Leprosy</td>
<td>100,000</td>
<td>515,000 (2003)²¹</td>
<td>$113 million from G20 countries and Novartis (2000–2020)</td>
</tr>
<tr>
<td>Clubfoot</td>
<td>200,000</td>
<td>181,000 (1980)</td>
<td>Less than $100 million globally</td>
</tr>
</tbody>
</table>
Healthcare is a Human Right

Children born with clubfoot—and all children, with and without disabilities—have a fundamental human right to access medical care. For over a half a century, international human rights advocates and agencies have recognized the moral imperative of protecting the rights of children and all people living with disabilities. Yet, little has changed in that time for children in LMICs born with preventable (or treatable) disabilities like clubfoot. This is not only an issue of social inclusion, but of the fundamental right to access health services that support an individual’s highest-attainable quality of life and functioning.

Since 1948, the United Nations has released four declarations to recognize the rights of people with disabilities. In 1989, the UN Convention on the Rights of the Child (CRC) became the first binding international law instrument to protect the rights of children, including those with disabilities. Article 23 calls on party states to safeguard the rights of children with disabilities “to enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.” With 196 party states, the CRC is the most widely ratified human rights treaty in history. This legislation advocates for healthcare for children with disabilities but does not provide financial support for pediatric disability programs and interventions.

The United Nations announced the Sustainable Development Goals (SDGs) in 2015 for member countries to frame their development agendas and political policies over the next 15 years. Each of the 17 goals includes several indicators to measure progress and targets to
determine success. The goals offer a roadmap to achieving disability-inclusive development. Six goals and 11 indicators explicitly refer to persons with disabilities and call for the holistic inclusion and empowerment of people with disabilities across a wide range of development sectors.

The UN legislation and Sustainable Development Goals lay the groundwork for the support of people with disabilities, yet clubfoot remains woefully neglected. If we are to reach the ambitious goals set out by the UN and work towards a more equitable future of health, we need action-oriented plans and funding. As long as there is inequitable access to treatment we will not see the practical manifestation of healthcare as a human right.
Global Investment Can Solve the Global Clubfoot Burden

Whether by surgery (until the early 2000s) or through the Ponseti method thereafter, the fact that clubfoot is highly treatable is what makes it virtually hidden from public view in countries like the United States and other developed nations. Of the 550,000 people living in the US today who were born with clubfoot, virtually all benefited from some form of treatment.

Together we can facilitate the same outcomes in LMICs. Clubfoot has remained largely absent from the priority lists of government and large foundation donors, as well as the multilateral organizations that set global health agendas. While addressing clubfoot aligns with UN and WHO initiatives, clubfoot has not benefited from a dedicated strategy or campaign bolstered by multilateral support. In fact, despite how common it is, clubfoot is not even measured or tracked as a discrete condition by the influential Global Burden of Disease (GBD) Study, making it more difficult to measure and compare its share of the disease burden in LMICs.

Engaging local partners and providers, expanding access to services, and integrating treatment into the existing public health systems has enabled treatment for tens of thousands of children in LMICs between 2000-2022. Thanks to targeted efforts by MiracleFeet and its local partner NGOs, several LMICs are already reaching more than 50% of babies born with clubfoot, including Tanzania, Bangladesh, Liberia, Paraguay, Nicaragua, Zimbabwe and Sri Lanka. Twenty years from now, with wide scale investment and action, we can prevent millions of children from living with this disability. An investment of $160–$200 million over the next twenty years can ensure every child born with clubfoot receives the care they deserve. This is a fraction of what has been spent to end other conditions that have comparable impact on a child’s quality of life. By doing so, we can prevent a painful lifelong disability, and transform the trajectory of young lives around the world forever.
About MiracleFeet

MiracleFeet is the largest global non-profit organization working to ensure that every child born with clubfoot has access to the medical care they need to thrive.

MiracleFeet partners with local health workers and organizations to bring the inexpensive solution — costing only $500 USD per child on average — to children who need it. Treatment is provided for free or at very low cost.

Founded in 2010, MiracleFeet has already helped transform the lives of 82,000+ children across 300+ clinics in 35+ countries.
References


