

LEISHMANIASIS – A NEGLECTED, GLOBAL DISEASE OF MARGINALISED PEOPLE

A summary report from the Leishmaniasis Gap Analysis Report and Action Plan
carried out in Albania, Jordan and Pakistan 2015

CORDS

Connecting Organizations for
Regional Disease Surveillance



UNITE FOR CAUSE



Our goal is to raise awareness about the millions of people suffering from leishmaniasis, and address barriers to its treatment and prevention. We need more action and a stronger political commitment to end the needless suffering of millions.

“We believe a rapidly changing world demands a pro-active and systematic approach to addressing the various contributing factors to disease proliferation. Therefore, we advocate and support a co-ordinated One Health approach to interventions”.

Prof Nigel Lightfoot CBE,
Executive Director of CORDS Network





A NEGLECTED DISEASE OF MARGINALISED PEOPLE

Today, at a time when diseases such as Ebola, MERS and Asian flu epidemics are prevalent, there's an increased awareness of the impact of infectious diseases as a global health threat and the devastating effect they can have on communities ill equipped to deal with outbreaks.

Leishmaniasis is prevalent in 98 countries on five continents

WHO¹

Leishmaniasis, one of the world's oldest recorded diseases dating back to the 7th century BC, is an entirely treatable parasitic disease spread by sandflies. There are estimated to be around 1.6 million new cases each year across 98 countries. The cutaneous form of the disease can lead to distressing and disfiguring skin ulcers and scarring, while visceral leishmaniasis, which affects organs such as the liver and spleen, is invariably fatal if not treated. Over 40,000 people die from the disease every year, making it the second-largest parasitic killer in the world, after malaria.

Unfortunately, despite its worldwide prevalence and disastrous impact on the lives of millions, leishmaniasis is still very much an emerging neglected disease, mainly affecting impoverished communities, living in poor conditions, without adequate access to shelter, healthcare and medication.

Climate change is increasing the range of insect vectors including sandflies while the mass movement of people in endemic areas due to conflict, famine or drought is putting increasing numbers at risk. Leishmaniasis has been ignored largely because of its association with poverty and the limited capacity of governments and aid agencies to deal with its complex epidemiology.

Until recently, it has also been a low priority for multinational pharmaceutical companies to invest in research to develop effective vaccines and therapies.

Leishmaniasis is an entirely treatable parasitic disease spread by sandflies, second only to Malaria

WHO¹

This is a summary of key findings and recommendations from the full **Leishmaniasis Gap Analysis Report and Action Plan** in Albania, Jordan and Pakistan. The analysis was carried out by regional disease networks SECID/SEEHN, MECIDS and Pak One Health over the course of 2015.

Its aim is to strengthen the capacity of the national health services for the treatment and control of leishmaniasis based on One Health principles.

The country assessments in the Report focus on the priority interventions as defined in the "Strategic framework for leishmaniasis control in the WHO European Region 2014-2020."

Within this framework, both qualitative and quantitative analyses were conducted to identify the major gaps in surveillance, diagnosis, treatment and prevention in each country's specific context.



The Gap Analysis Report is unique in a number of ways:

- 1 It addresses both forms of leishmaniasis: cutaneous leishmaniasis (CL), which can cause severe disfigurement, and visceral leishmaniasis (VL) which can be fatal if left untreated. Traditionally considered as separate diseases, studying CL and VL together can increase the potential for collective action against the total disease burden of leishmaniasis and other vector borne diseases such as Dengue Fever and Zika virus.
- 2 Our report has facilitated collaboration across three distinct geopolitical areas, the Middle East, Europe, and Asia.
- 3 It represents extensive collaboration and sharing of lessons learned by the Republic of Albania (part of the SECID/SEEHN Network: Southeast European Centre of Infectious Disease Surveillance and Control/South East Europe Health Network), The Hashemite Kingdom of Jordan (part of MECIDS: Middle East Consortium on Infectious Diseases), and the Islamic Republic of Pakistan (POHA: Pak One Health Alliance) on operational programming and research.

The Report has been developed in partnership with CORDS Network with funding from the Bill & Melinda Gates Foundation.



WHAT IS LEISHMANIASIS?

There are three main forms of Leishmaniasis; cutaneous, visceral (or Kala-azar) and mucocutaneous.

Visceral (kala-azar) is characterised by high fever, substantial weight loss, swelling of the spleen and liver, and anemia. If left untreated, the disease can have a fatality rate as high as 100% within two years.

Cutaneous is the most prevalent form, causing ulcers on exposed areas, such as the face, arms and legs. These usually heal within a few months, leaving scars. Diffuse cutaneous leishmaniasis produces disseminated and chronic skin lesions resembling those of lepromatous leprosy. It is difficult to treat.

Mucocutaneous, found mainly in South America, invades the mucous membranes of the upper respiratory tract, causing gross mutilation by destroying soft tissues in the nose, mouth and throat and surrounding tissues.



A DISEASE OF IMPOVERISHED PEOPLES

A disease of impoverished peoples

Leishmaniasis is highly correlated with poverty, malnutrition and other diseases, which affect immunity, as well as factors such as crowded living conditions and poor sanitation. Additionally, children and immune-compromised adults with existing co-morbidities notably HIV/Aids are more susceptible to becoming infected.

Leishmaniasis is transmitted through the bite of infected female sandflies which breed in a variety of habitats including forest areas, the burrows of small rodents and human and livestock shelters. Climate change, deforestation, rapid urbanisation, and population movement are factors affecting the spread of leishmaniasis by increasing human contact with sandfly vectors and reservoir host populations such as dogs and rodents.

Conflict in regions endemic to leishmaniasis contributes to the displacement of large groups of vulnerable people, which in turn contributes to the proliferation of the disease. It is therefore unsurprising that the ongoing conflicts in Afghanistan, Syria and the Horn of Africa have all seen an increased incidence of leishmaniasis among those affected.

Leishmaniasis cannot be transmitted directly from an infected person or animal to another person. Rather it requires the presence of female sandfly vectors to spread the disease. It is not therefore a disease that is likely to spread in areas such as Western Europe, which generally lack sandflies and have healthy populations with good sanitation and access to high-quality healthcare. Leishmaniasis is very much a disease that affects impoverished communities living in poor conditions

Silvia Bino MD, PhD, SECID

The real health burden of leishmaniasis remains largely unknown with only 600,000 of the estimated 1.6 million cases each year being diagnosed and treated. This is because those who are most affected are from marginalised communities in rural areas or urban slums, who are unable to seek medical attention because of cost and lack of access to treatment.

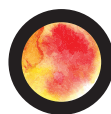
Social and psychological impact

In addition to physical symptoms, there are psychological and social stigma from the ulcers and scarring of CL, which can lead to exclusion from society due to the mistaken belief that the disease is directly contagious, or because it can be easily mistaken for conditions such as leprosy.

Mothers with cutaneous leishmaniasis may refrain, or be prohibited, from touching their children; young women with disfiguring facial scars are often considered unsuitable for marriage and the disease may provide the pretext for a husband to abandon a wife. Children with the condition can miss out on their education because of concerns that they may infect others at their schools.

Approximately 1.3m new cases occur annually. Of these only about 600,000 are actually reported

WHO¹



LEISHMANIASIS GAP ANALYSIS - KEY FINDINGS

Albania

In Albania, VL remains predominantly a paediatric disease in impoverished rural communities. 68% of new cases are detected in children under the age of 5 years, and 80% in children under 10. While the incidence of VL in Albania has decreased in recent years, it remains the highest in Europe.

Between 2000-2014 there have been a total of 1,368 cases, 956 of which are children from 1-14 years.

In Albania, VL is zoonotic with dogs acting as reservoir hosts needed to maintain the disease in infected areas. Breaking the cycle of human infection therefore requires effective control of the disease in dogs.

We need to focus on developing a One Health approach to:

- Improve early detection and treatment of visceral leishmaniasis cases by training frontline public health workers;
- Co-ordinate with the all government structures and municipal authorities and other to develop programmes to control sandflies and feral dog populations and treat dogs which carry the disease;
- Run public awareness and risk reduction campaigns in affected areas ensuring an adequate supply of safe and effective anti-leishmania drugs to treat all patients.



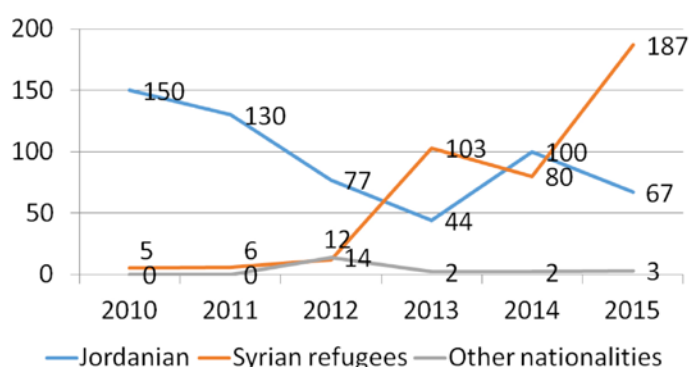
LEISHMANIASIS GAP ANALYSIS – KEY FINDINGS

Jordan

Zoonotic CL (ZCL), the predominant form of the disease in Jordan is mostly confined to the Jordan Valley where rodents act as a wildlife reservoir. Although awareness is high in endemic communities, patients often initially resort to ineffective traditional remedies leading to delays in seeking medical treatment. This results in an increased risk of residual scarring and disfigurement.

Jordan, like Lebanon and Turkey, which also host large numbers of Syrian refugees, is at significant risk of anthroponotic cutaneous leishmaniasis (ACL) becoming established, firstly among the impoverished refugee populations and subsequently in host communities. Unlike ZCL, ACL does not require a reservoir host and can therefore become established in urban environments.

Trend of CL cases by nationality, 2010–2015, showing the effect of Syrian conflict on reported cases in Jordan



310 million at risk of infection from Leishmaniasis in the six countries reporting over 90% of VL cases worldwide

WHO!

To prevent this from happening, the capacity of the health services to detect CL cases early and treat them effectively needs to be improved. This will be particularly challenging given the marginalised status and transient existence of many refugees.

A joint MoH (Ministry of Health) /MoE (Ministry of Education) in-service training programme for teachers who come into daily contact with students has been proposed as they are well placed to be part of an early warning system.

Training will help familiarise them with the typical appearance of CL lesions so that suspected cases can be referred to the school medical officer for further treatment and follow-up.

Jordan aims to prevent the spread of CL through targeted follow-up workshops to improve surveillance and promote the use risk reduction measures, particularly among those living in and visiting endemic areas.

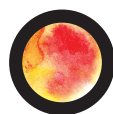
Pakistan

There are an estimated 50,000 new cases of cutaneous leishmaniasis (CL), the predominant form of leishmaniasis in Pakistan, each year. This appears to be an emerging disease, initially prevalent in refugee communities from Afghanistan, which has also become established in host communities in Balochistan and elsewhere in north-west Pakistan.

A key problem in Pakistan is a lack of access to low cost, quality assured drugs to treat the condition, particularly in deprived communities. This has resulted in a market for counterfeit and smuggled drugs of dubious quality, which can have harmful impacts on those being treated.

In Pakistan, the key interventions identified in the gap analysis are to:

- Provide effective and timely treatment of the estimated 50,000 new CL cases each year;
- Improve the quality of lives for those currently living with this disfiguring and socially ostracising disease;
- Prevent further transmission, especially in communities on the Afghanistan and Pakistan border;
- Investigate opportunities for accessing subsidised medication.



A ONE HEALTH APPROACH

A major barrier to the treatment of leishmaniases is that it is a low priority for governments and health authorities with limited budget and resources allocated to communities in areas where it is prevalent.

As such, co-ordinated efforts are needed to raise awareness and interest, as a critical step in addressing the major gaps identified in the treatment and prevention of this and similar vector-borne diseases.

One area that urgently needs to be addressed is for governments in Albania, Pakistan, Jordan and other affected countries to change their regulations to enable the registration and importation of anti-leishmanial drugs into their countries.

In Pakistan there is also an urgent need to build corresponding capacities (skills, services, equipment and drug supplies) to improve detection and response to vector-borne diseases.

In Albania, we will focus on the prevalence of leishmaniasis in children in poor, rural areas and the need to develop programmes that both treat carriers (dogs) as well as treating those with the condition. (SECID has identified a pediatrician who is happy to be interviewed by the media).

In Jordan, the focus should be on the significant risk of ACL (anthroponotic cutaneous leishmaniasis) becoming established in refugee and host communities and innovative approaches working with schools to spread awareness and identify those needing treatment.

We need a One Health Framework that delivers:

- Increased awareness of the various forms of leishmaniasis (amongst governments, health organisations and the public in affected areas);
- Better co-ordination between governments, animal and human health organisations and NGO's;
- Better and more sustainable access to diagnostics, treatment and medication;
- More affordable treatment available in communities where leishmaniasis is most prevalent;
- A proactive programme for vectors and reservoir hosts carrying leishmaniasis in affected areas;
- Funding and government buy-in is needed to implement the report recommendations to help halt the spread of this treatable condition which has such a terrible impact on the health of marginalised populations in affected countries.

Up to 40,000 people die from visceral Leishmaniasis each year

WHO¹

Recommendations

1 Sustained resources: improving access to lower-cost treatments. WHO has negotiated an arrangement with a number of pharmaceutical companies whereby low-income countries, UN agencies and certain NGOs can purchase anti-leishmania drugs at substantially discounted prices.

The reasons why Pakistan, as a low-income country, is not availing itself of this scheme need to be investigated. Indeed, all three-project countries should question their eligibility, either directly or through participating NGOs or UN agencies, to ensure that anti-leishmania drugs are available for those who cannot afford to pay for them, without putting an unsustainable financial burden on the public health budget.

2 Real-time, open-access data: significant investments of time, human and financial resources are required to support open-source, data exchange protocols between network partners.

The Leishmaniasis Virtual Group (Leishmanix.net) has been created to address this need. It is a platform in which research findings and epidemiological surveillance data can be shared in real time between countries, networks, and Ministries of Health across geo-political borders.

3 Integrating One Health principles into the agenda of existing coalitions: the need for a co-ordinated multi-sectoral "One Health" approach for the control of leishmaniasis is universally acknowledged. The Pak One Health Alliance (POHA) has shown itself to be an effective mechanism for bringing relevant stakeholders together and initiating the debate, which ultimately led to this Gap Analysis project. It is recommended that other countries in MECIDS and SECID/SEEHN networks develop similar forums, appropriate for their particular situation, to enable "One Health" principles to be applied to leishmaniasis, as a model for other diseases.

4 Policy change: due to a lack of awareness of leishmaniasis and its impact, none of the project countries have a clear national policy, or a dedicated budget for leishmaniasis. This was identified as a major constraint requiring advocacy and commitment at the highest level of government to bring about change.

Leishmaniasis has many similarities with other vector borne diseases such as malaria and dengue in terms of core component activities including surveillance, data management, epidemiology, vector control, public awareness and risk management. Therefore, improvements in the management of leishmaniasis should be presented in the context of a broader national vector borne disease strategy.

This would raise the profile of leishmaniasis and provide access to personnel and resources available for other vector borne disease programmes. In addition, improving the capacity to manage a real and present disease like leishmaniasis will, de facto, enhance epidemic preparedness and the ability to respond to other emerging disease threats such as Zika.

Next steps

CORDS is a unique organisation whose mission is to connect multi-country infectious disease surveillance networks to improve capacity to detect epidemics earlier. It does this by working with its regional disease network partners through a One Health principle and at a local level by engaging communities and giving them a say.

We have set out what the countries would like to happen and are prepared to do to alleviate the suffering. However, the policy changes and initiatives highlighted will need more funding and government commitment for this to happen. This is the beginning of our journey to tackling this growing infectious disease, which has had such a disastrous impact on the lives of so many. The time for action is now.

We would be happy to provide further information and in-country contacts to potential funders. For more information you can reach us at info@cordsnetwork.org

References

¹ All statistics provided by World Health Organisation (WHO)