Leishmaniasis – one health cross sectoral, cross border and cross network group

Interim report

Prepared by SECID

Leishmaniaisis a zoonotic vector borne disease with endemic transmission in <u>Middle East and Southern Europe</u> where MECIDS and SECID network are established has been chosen as an important disease with an important public health impact to establish a one health, cross sectoral, cross border and cross network group. To establish such group several steps have been taken during the last year

- **Agreement and decision to establish of a virtual one health group based on a designed web based platform. The aim was of this imitative** was to establish a network of experts on Leishmaniasis from various sectors and build a regional system for Leishmaniasis surveillance, knowledge sharing, multisector collaboration and international cooperation that will improve Leishmaniasis control in both regions.

- **The general objective of virtual one health goup was further prepared and discussed with both network under the leadership of CORDS and SECID and it is to provide a platform for Leishmaniasis experts from various sectors and countries of the Mediterranean region to share knowledge, data and increase capacities and awareness on Leishmaniasis.** The decided **specific objectives** were as follow:

- <u>Objective 1</u>: establish a digital platform for leishmaniasis experts from different sectors and countries;

- *Activity 1*: develop a web based platform to create and promote discussion among experts;

- *Activity 2*: assign an overall coordination/management committee to decide on the various topics that will lead the discussions;

- *Activity 3*: appoint one coordinator to coordinate the discussions and platform activities and project preparation

- *Activity 4*: develop the users' manual for platform participation;
- *Activity 5*: maintain the website (IT work) and share and discuss projects, best practices and data.
- <u>Objective 2</u>: establish an innovative way for knowledge sharing for capacity building and problem solving;
- *Activity 1*: develop and maintain a resource library on the website for document upload;
- *Activity 2*: encourage the discussions and documents upload based on various subjects;
- *Activity 3:* discover new technology and control methods, lessons learned/gaps;
- *Activity 4*: share best practices, innovations and lessons learnt;
- *Activity 5:* encourage interactions between experts to solve issues and problems as brought up by group members;
- <u>Objective 3</u>: improve awareness and funding on Leishmaniasis and further project development
- *Activity 1*: establish a proposal writing/fundraising group;
- *Activity 2:* actively searching for funding opportunities;
- *Activity 3:* identify experts to determine the social and economic burden of Leishmaniasis in both regions;
- *Activity 4:* conduct the health economics and social analysis and use results to raise awareness on leishmaniasis;
- *Activity 5:* prepare papers and information materials based in important issues discussed by the leishmaniasis experts;
- *Activity 6*: proposal writing/fundraising group to hire a grant writer to apply to selected funding opportunities.
- <u>Objective 4</u>: use knowledge discovery process to establish a database for gathering of published and unpublished data
- *Activity 1*: establish common standards/protocols for data gathering and processing;

- *Activity 2*: develop a database capable to accommodate data retrieved from published and unpublished literature;

- *Activity 3:* collect information from published and unpublished papers and fill in the database;
- *Activity 4:* update existing information on leishmaniasis spread and create map/graphs of leishmaniasis cases, reservoirs, vectors and control measures.

- **The proposal for web based platform and its organization has been developed and approved.** The platform was developed by IT team of SECID and has been extensively discussed among SECID members (mainly Albania, Bosnia and Herzegovina and Bulgaria) with the contribution of MECIDS countries: Israel, Palestine and Jordan. **The platform was presented in different conference calls and launched during One health : Leishmaniasis and surveillance meeting in November, 2014, in Tirana, Albania**

- **A manual on how to use the platform** has been prepared and distributed

- **A   coordination committee** with various experts woth strong participation of CORDS, MECID and SECID has been established **during One health : Leishmaniasis and surveillance meeting in November, 2014, in Tirana, Albania**
- A selection process to appoint one coordinator to coordinate the discussions and platform activities and project preparation has been established with participation of CORDS, MECID and SECID.
- A coordinator to coordinate the discussions and platform activities and project preparation has been selected and has alredy started to work based on ToR already prepared by SECID and discussed with CORDS and MECID.

- A resource library on the website for document upload has been established and few papers or unpublished data are already uploaded
- **One health : Leishmaniasis and surveillance meeting was organized in 29 -30 October , 2014, in Tirana, Albania** to present a web based Leishmaniasis, one health information and communication platform and discuss further collaborative initiatives with partners, donors and stakeholders.

  The objectives of the meeting were:

1. To increase the awareness of Leishmaniasis the second parasitic killer in the world after malaria by using the communication and information platform.

2. To improve one health communication and cooperation within SECID and among MECIDS, SECID and APEIR.

3. Use the web based platform to improve one health surveillance and control of Leishmaniasis as a model to be applied to other priority diseases.

4. To promote and discuss future one health cross network initiatives

The meeting was attended by a wide range of cross sectoral experts form SECID and MECIDS countries, Belgium, Italy, Greece, Pakistan,USA etc.

Different presentation addressed the challenges of Leishmaniasis as an important public health problem in Southern Europe and Middle East as well as other regions such as Pakistan, its diagnostic challenges, the importan role of vectors and the challenges of surveillance of vectors, animals and humans, the burden of Leishmaniasis and its social impact, the impact of dog control programs and the role of the media. The process of establishing the platform has bee described in the meeting as well as the platform itself and different uses.

The following conclusions were from different working groups:

1. *How Lx platform can contribute to promote Leishmaniasis control and decrease the burden of disease*

This group concluded that more information is needed to understand the platform, put it into practice, and prepare messages for public consumption. The platform cannot simply reflect scientific interest in the disease, but must project conviction that the disease can be made accessible and understandable to the global community as a way to address the burden of leishmaniasis.

2. *How Lx platform can be used to address the operational and research challenges of Leishmaniasis in Europe and Middle East.*

To appeal to policymakers and institutions in individual countries, the Lx platform can summarize findings and research and awareness campaigns. To make the project real, we need to work to put research onto the platform, create a central place for discussion and analysis, and establish research priorities.

Challenges include access and ability to publish, even on a secure website, national data and trends. However, we can work to secure memoranda of understanding from ministries and strive to standardize protocols and draw on VBORNET's resources for doing so, which would serve as a leading example for countries. Other challenges include: the massive effort needed to project Lx as a One Health resource (data from three sectors needed for this); obtaining funding to sustain research and an in-person networking through a conference. Analysis of historical data will aid research as the basis for a proposal. To manage all of these activities, Lx needs someone to act as coordinator.

A commenter agreed that the group is correct to be concerned about who will use the site. For that reason, we should put forth a robust effort to focus on One Health and put leishmaniasis in the context of a disease that is driven by factors in all sectors.

3. *How to improve the one health web based platform to address all Leishmaniasis control challenges.*

This group focused on the platform as a public resource. By broadcasting packaged messages to target groups, and reinforcing these messages via Facebook and Twitter, we can establish an effective risk communication campaign. Specifically, the platform should contain messages for parents and teachers about how to raise dogs properly and give information about responsible and safe dog ownership. The site should also serve as a resource for clinicians treating patients with Leishmaniasis.

 To increase exposure, we can project a more inviting layout and include keywords on the site that result in prominent position on Internet search for "leishmaniasis".

During the second day data challenges in SECID and MECIDS countries and need for cross border collaboration in SECID and MECID countries - Albania, Macedonia, Kosovo, Bulgaria, Croatia, Jordan, Palestine, Israel, Thailand, Georgia, Pakistan were discussed as well as two projects were presented :

1. Surveillance and risk assessment (Cross border Cooperation) by Laor Orshan, Ministry of Health, Israel.

2. Case control study including vectors and reservoirs in Albania by Kujtim Mersini, Institute of Food Safety and Veterinary, Teita Myrseli, Institute of Public Health, Albania

During the working groups the discussion were as follow:

1. *How to maintain an active platform and further improve it and extend it to other countries*

We should think of the platform as a wheel, with the platform acting as the hub and the contributing experts, countries, and institutions acting as the spokes. We should identify a coordinator in each country to lead contributions and offer input on behalf of other participants in the same

country. We could also solicit input and contributions from students and encourage partnerships with them and their academic institutions. In this way, we can build a dynamic local/global interface. We can also promote to ministries, companies, and foundations a set of harmonized protocols for diagnosis, treatment. Engaging the other CORDS networks would give us access to a broader set of decision makers.

2. *Data query, challenges of standardization and using a web based platform for data sharing.*

Two basic challenges to standardization and utility of the web platform are: accessibility of full datasets; the identification of demographic parameters across countries; the production of maps and graphs from available and uploaded data; and the resistance/reluctance of health ministries to share data. To share data, it has to be de-identified. SECID maintains memoranda of understanding with members countries' governments that enables access to data. In other countries, however, and available data is limited in quality and geographic scope.

3. *A scientific advisory group and their role to improve the platform and guide further work.*

The scientific advisory group will guide the research aspect of the platform by continually providing input and steering research towards ambitious but achievable objectives. Scientific advisors should represent the expertise across the VG and not necessarily represent the constituent countries. We will choose individual members once all members have the opportunity to review and provide input on the draft proposal.

The geographic scope for further work was narrowed to contiguous areas in the Jordan Valley, which includes parts of Israel, Jordan, and Palestine (CL) as well as explore the situation with Syrina refugies; and the Kukës region that

serves as the border between Albania and Kosovo (VL). By soliciting the input from multiple countries, we can advance the VG initiative's cross-border objectives. The CORDS programme manager will coordinate regular information exchange and video teleconferences among the scientific advisors and wider research group. The VG coordinator will incorporate the work of the scientific advisory into the overall work of the VG.

A commenter asked how this plan was operational, since it seems to lack a practical result. The group's response is that the research would be the basis for outreach to ministries to implement smarter and effective policies to lessen the burden of CL and VL.

At the close of the meeting, the group pledged to continue the work of the Virtual Group, and as a first step, to register with Leishmaniax and until now 30 people are already registered.

Also two other projects related to situation on Syrian refugees and situation and use of bed nets in Pakistan have been prepared. All projects are within the platform for further discussion and funding.

Also, the group adopted a mission for the Virtual Group: *To widen the coalition of experts to target and address the burden of Leishmaniasis.*

The developed platform is an open one for all contributors and experts but a request for memebership is needed to have a username/password to protect the confidneciality of some of the materials that contains data that cannot become immediately public.

Until now we do have only documents containing some data both quantitative and qualitative and a database has not yet been established in this phase as previously as it was not the aim of the platform. So the datasets will be discussed in the coming months and will be decided which of them will be available for public access and also the requirement criteria for datasets made available for public access and stored electronically will be established.

Until now **appropriate measures are taken to protect individual and personally identifiable information in the platform and the materials**

containing data will be accessible for 5 years from date of being lodged with a data repository or similar platform inn cases where access will be limited to a specific set of users.

The timely access to data will be finalized in June and will be ready for public access. Meanwhile the platform and all raw material is already finalized and available for public access. Some agreements have been identified during the meeting to access or use the datasets even for some raw material within the platform. Also a preparation of the cost to prepare, maintain and make datasets accessible and provide their storage for a period of five years, at least will be prepared in the coming months.

A secured website has been ensured by IT company and it is an open source based and a manual for its use is open for everybody.

A report on activities performed within the platform will be available by the end of March.