

**Dear NTM-NET members,**

it has been too long that I informed you about current developments of the NTM-NET. There are enough reasons to do this now:

- **Biennial NTM-NET meeting on Saturday 9<sup>th</sup> of September in Milano**

First of all be invited to the next biennial NTM-NET meeting at the day of the opening of the ERS in Milano. The location will be a in the north-east of Milano, at the [Ospedale San Raffaele](#). You will find [informations on venue, access & program](#) on our [meeting webpages](#) within the coming weeks. Please save the date, send us suggestions for the program, and register with [cehlers@fz-borstel.de](mailto:cehlers@fz-borstel.de).

- **Ending term of chairing the NTM-NET – Upcoming Elections**

The constitution of the TBnet calls for change of positions in the Steering Committee every three years. This includes the position of the representative for NTM in the TBnet SC. Since the NTM-NET is a branch of the TBnet and we do not want to change this, this position in the TBnet SC is at the same time the position as chair of the NTM-NET. After two successive terms of being the chair of the NTM-NET it is mandatory according to the constitution and at the same time seems to be time for a change in this position, to allow new ideas and energy lead to a further development of the NTM-NET.

The constitution of the TBnet requires the new positions of the SC to be elected during TBnet membership meetings, e.g. the elections are taking place during the TBnet meetings by show of hands. The next TBnet meeting will take place on the 8.9.2017 in Milano, Friday before the NTM-NET meeting. Therefore I would like to have NTM-NET members choose the new NTM-NET chair before this TBnet meeting.

In the coming weeks the TBnet will send out requests for candidates of the upcoming positions of the SC including that for the NTM-representative of the TBnet SC. Please find attached the respective job description of the NTM-NET chair. Those who will step up for one of these positions, will have to do so until end of August, however I would request those who want to **apply for the chair the NTM-NET** to do so latest **until July 31<sup>st</sup> 2017**. Please include a short covering motivation letter, a CV and send it to Cordula Ehlers ([cehlers@fz-borstel.de](mailto:cehlers@fz-borstel.de)) as well as to myself ([Dirk.Wagner@uniklinik-freiburg.de](mailto:Dirk.Wagner@uniklinik-freiburg.de)). We will use an online survey tool (e.g. survey monkey or similar) to present the respective candidates and ask for the vote of the NTM-NET members **during the month of August** in order to present the selected candidate at the TBnet meeting, where the present members can officially “vote” for or against the proposed candidate.

- **Chairing the NTM-NET**

The previous years of chairing the NTM-NET showed that leading the NTM-NET as a single person is not as effective. New ideas and separated responsibilities would allow more input to push new developments and new studies, which are urgently needed. The pediatric TBnet also has changed to a

steering committee, e.g. several people being responsible. This discussion, whether and - if yes - which positions should be created, and the election of respective willing members will take place at the NTM-NET meeting in Milano. So please be ready for this discussion, think about which positions should be created and think about whether you would like to step up for a respective mandate.

One new position has already been decided: There is a need for secretarial support of the new NTM-NET chair. This secretary will be responsible for communications, secretarial work and the webpage. Also in order to allow a smooth transition, and since I am most familiar with the structure and the webpage, I myself would like to step up for this position. I would like to ask you to voice opposing opinions during the NTM-NET meeting or – if you are not able to attend the meeting – to write me and I will voice these during the NTM-NET meeting.

## ▪ **NTM-registry**

In 2015 the application of NTM-NET with EMBARC for a NTM-registry as an ERS Clinical Research Collaboration was not supported by the ERS. The idea however remained vivid and evolved without support of the ERS as a registry funded by EMBARC. We as NTM-NET are actively involved with the PIs being Michael Loebinger, Charles Haworth and Jakko van Ingen. Michael will present the registry and the current status at the NTM-NET meeting on 9<sup>th</sup> of September. I myself am very much in favor of this registry since I believe it will be a step forward in the understanding of the disease, but also being a requisite for inclusion of patients in prospective studies. I therefore want this EMBARC-NTM-NET-registry to become a success-story and will actively support it and engage myself in this endeavor in the forthcoming years.

## ▪ **NTM studies**

The number of running studies is at a low level. I see many collaborations but only few are making use of the NTM-NET. We need to think about ways to increase the attractiveness of the NTM-NET to do collaborations. Everybody should ask her/himself whether a collaborative study that you plan or think about would be a good candidate as an NTM-NET study. Without common studies the network will not prosper and/or develop. We will devote some time of the NTM-NET meeting to discuss and generate ideas how to better support collaborations, if you plan to participate in the meeting please think about this ahead of time. If you are not participating, and have ideas, please share these with me so I can present them at the meeting.

## ▪ **NTM-NET Clinical Study Sites and NTM-NET Clinical Study Contact**

In the forthcoming years will see a development of several new antimicrobial agents for NTM-PD. I envision the development of certified NTM-NET clinical study sites (NTM-NET CSS) that have the ability to participate in studies according to GCP. It would be easier for anybody initiating a therapeutic trial if study sites and responsible persons at the site already existed and would be ready to participate – and

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the NTM-NET could be a harbor of these sites. I have already proposed this at the last NTM-NET meeting but did not have the energy to bring this forward. I therefore will propose at the NTM-NET meeting to create the position of a representative of the NTM-NET (e.g. a NTM-NET clinical study contact, NTM-NET CSC) who would be responsible for the development of this infrastructure (with the help of the NTM-NET chair and NTM-NET secretary) and would be the primary contact person. This also will be discussed at the NTM-NET meeting.

- **NTM-NET webpage**

We are in the process of upgrading the webpage to the newest Joomla version and at the same time splitting the NTM-NET page from the TBnet page which is a prerequisite for a mobile version (which needs to be created). I do not know yet how we will change the access to the site – it will still be mandatory to become TBnet member in order to become NTM-NET member. What is clear that the NTM-NET map has to be recreated. E.g. everybody needs to log in to the new webpage (lets say in August) and pinpoint in their personal profile page on the map the location of her/his office – please do it ALL of YOU. At this time you could please check and correct your personal data.

The webpage is not used a lot although there are many tools available. If you log into the members area, you will find the option to chat, to have a forum, to have a NTM consultation. The webpage development including these tools has been in my hands from the beginning, but this is rather learning by doing. So it would be great if I had a second person who is knowledgeable in content management systems (like Joomla, which we are using) to help in uploading content, creating the mobile version and new pages for new studies and managing the membership tools. So if one of you is interested in helping – please let me know!

I would love to see this members-area to be used more. So please check it out and think about what could be improved and what is missing. This also is going to be discussed at the NTM-NET meeting.

So please be invited to attend this NTM-NET meeting in Milano on September 9<sup>th</sup>, please register with Cordula ([cehlers@fz-borstel.de](mailto:cehlers@fz-borstel.de)) early that we can better plan it. If you are not able to attend, please give feedback or input – because this is what we need: active membership.

Best regards,

Dirk