Aynur Ayşe KARADUMAN <ayse.karaduman@lokmanhekim.edu.tr>

TREAT-NMD SMA Core Dataset Project (Year 3)

2 ileti

Julie Bohill <julie.bohill@newcastle.ac.uk>   13 Aralık 2021 15:58
Alıcı: "ayse.karaduman@lokmanhekim.edu.tr" <ayse.karaduman@lokmanhekim.edu.tr>,
"reda.tunc@lokmanhekim.edu.tr" <reda.tunc@lokmanhekim.edu.tr>

Dear Ayse & Azize,

I would just like to follow up with you following the earlier email sent from Joanna Das.

I wonder if you've had a chance to consider whether you would like to participate in Year 3 of our project?

All TGDOC member registries are now being asked to comply with the SMA Core Dataset v.2, or begin working towards it and the *Dataset Implementation Project* can help you by providing financial bursaries (upto €8,000) alongside expert guidance and support to achieve compliance.

Can I please ask you to confirm if you are now collecting the V2 dataset and if so could you provide an excel copy of your data collection form so that we can confirm this. If you are not currently collecting the core dataset, would you like to work towards the collection of this with our support and be one of the registries in our Y3 programme.

I very much look forward to hearing back from you on this.

Kindest Regards,

Julie Bohill

Julie Bohill

TREAT-NMD SMA Dataset Project Manager

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Please note my usual working days are Mon- Wed

From: Joanna Das <Joanna.Das@newcastle.ac.uk>
Sent: 21 September 2021 13:39
To: ayse.karaduman@lokmanhekim.edu.tr; reda.tunc@lokmanhekim.edu.tr
Cc: Julie Bohill <julie.bohill@newcastle.ac.uk>; Julie Bohill <julie.bohill@treat-nmd.com>; Joanna Das <Joanna.Das@treat-nmd.com>
Subject: TREAT-NMD SMA Core Dataset

Good Afternoon Ayse and Azize,

I hope this email finds you well.

I would like to formally invite your registry to participate in the final year (year 3) of the TREAT-NMD SMA Dataset Implementation Project, which will run to 31 May 2022.

As I'm sure you know, we significantly expanded the SMA core dataset in 2018, and all TGDOC member registries are now asked to comply with SMA Core Dataset v.2, or begin working towards it. The Dataset Implementation Project can help by providing financial bursaries and expert guidance, and our records show you have not yet benefitted from this support.

If this is because you have already implemented the expanded dataset, please let us know. If you have not yet implemented it, I strongly encourage you to take advantage of the support offered by this project, while there are still spaces available.

More information about this project, which has already supported almost 30 registries to implement the dataset, is available on the project web page.

Previous participating registries have found:

> *'Our impression regarding expanded dataset is very positive. Information it collects are valuable as well as the whole process of acquiring the information. It points to the potential weakness in data we collect, especially concerning patient history, and draws out issues that require more focus in the future thanks to their potential significance in improving the care for the patients as well as their academic and scientific value. Opportunities for improving were identified in the dataset workshop through discussions which hold great value for research.'*

'First we noticed an improvement in the quality of the data. More patients have been entered and data fields are more complete compared to previous collections for which we had a TREAT-NMD SMA section (using the v0 core dataset) in our general registry. Further, we received several requests for data from pharmaceutical companies within the context of a drug reimbursement application. Without the [SMA Core Dataset] we would not be able to answer these requests.'

'We know that working on an expanded SMA registry is very difficult, but at the same time very,very useful'

I now invite you to make contact with me the Dataset Project Coordinator Joanna Das (joanna.das@newcastle.ac.uk) to update your registry's current status and discuss the support we can offer.

Finally, I would like to mention the TREAT-NMD Global Registries Platform, which we will be using in future to accept and collate data from registries for our global enquiries. This Platform will also be available for TGDOC registries to use free of charge for their own local data collection and management, if they wish. To find out more or organise a demonstration, please contact Project Manager Caroline Ogden (caroline.ogden@treat-nmd.org).

Thank you for your attention.

Regards

Joanna

Joanna Das

TREAT-NMD SMA Dataset Project Co-ordinator

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*Please note that my normal working days are Tuesday, Wednesday, Thursday and every other Friday.

Aynur Ayşe KARADUMAN <ayse.karaduman@lokmanhekim.edu.tr>   17 Aralık 2021 11:05
Alıcı: Julie Bohill <julie.bohill@newcastle.ac.uk>

Dear Julie,
Thank you for the invitation. The LUKAM registry has already collected the majority of the V2 dataset of SMA. We need some support especially human resources to sustainability. I applied for a TREAT NMD bursary for this reason.
Best wishes.
Ayşe

Julie Bohill <julie.bohill@newcastle.ac.uk>, 13 Ara 2021 Pzt, 15:59 tarihinde şunu yazdı:
[Alıntılanan metin gizlendi]