

Wikipedia Epilepsy Project

Members

Editors-in-Chief

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ILAE Wikipedia Team

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Background

Wikipedia has a huge readership especially with respect to health-related information. Both professionals as well as lay people read health information on Wikipedia and it is important to ensure the quality of such information. Since ILAE plays a pivotal role with respect to work in the field of epilepsy, the ILAE Wikipedia Epilepsy Project is an initiative to ensure the scientific accuracy of the information on epilepsy related articles on Wikipedia.

Activities completed in 2020

1- Changing the management asset of the Project.

As the project continues to grow, there is a need for a better management of the people involved (writers/reviewers) together with a better planning of the Wikipedia entries to be edited as well as a greater involvement of social media.

Therefore, we are in the process of creating a board that will manage the Initiative. The board will be composed of the Editor in Chief (Ilae member), the Associate Editor in Chief (Yes member), the Publication Editor (Yes member), the Reviewing Editor (Ilae member), the Content Editor (Yes member), the Social Media Editor (Yes member), the Wikipedia Akatons Editor (Yes member).

This recruitment has been finalized. The related information as well as the detailed presentation concerning the workflow of the Editorial Board has been transferred to the new leadership team. Contacts of the people involved have been shared. Christos Lisgaras from YES oversees the YES activities in the Wikipedia Initiative. I talked to Christos and I instructed him to contact the new management team. To my knowledge the contact has been established and a zoom meeting has been set to discuss the role of YES in the vision of the new leadership.

2- Organization of the 2nd ILAE Wikipedia Epilepsy project workshop at the ECE 2020 in Geneva.

This was almost finalized till the COVID pandemic arrived and cancelled the meeting. The workshop was organized together with Amin Azzam and its structure was supposed to be similar to the workshop held in

Bangkok. I shared the contact of Amin Azzam with the new leadership team. Amin has already contacted the new leadership and shared information as well as slides and novel ideas. A zoom meeting is being planned between Amin and the new leadership to discuss further the workshop settings.

3- Upload of the report from the ILAE task force on women and pregnancy to Wikipedia.

The task force has requested to upload their recent work published in Epileptic Disorders into Wikipedia. This includes both the pdf paper as well as write a new entry in Wikipedia that would deal with the same topic but written in lay language. We have succeeded in getting the transfer of the publishing license from the journal publisher into the format compatible with Wikipedia (CC- BY-SA). This happened in the middle of the pandemic and thus the paper has yet to be uploaded. An author from the YES group that could write the new entry into Wikipedia has yet to be found. Both the paper and contact of Torbjörn Tomson (who oversees the task force) have been shared with the new leadership. A contact has yet to be established.

Challenges to consider for a successful advancement of the project:

1- Copyright/license transfer agreement:

This is a big issue, and it cannot be covered in a few lines. This topic was discussed in the past and it should be further discussed in the publication council. A possibility to consider is to create a dual publication model. Even though we discussed this issue in the past (executive board meeting in New York 2018), we still did not make any decision on the matter. Among the existing models, I suggest giving a further look on the model that PLOS Computational Biology uses to have dual publications both in their journal and in Wikipedia. To my knowledge this is the best model available today for a dual publication model. It might not work for all the ILAE journals, but this is certainly a platform to explore and possibly try to advance.

2- Recruit authors for editing\creating Wikipedia entries:

The collaboration with YES significantly improved this aspect. Therefore, I think that the role of YES in the project should be further supported and strengthened. In my view, the future of the whole initiative is in their hands. Their active involvement will allow the transfer of their support to their students once the YES members will be senior executives in the ILAE. Besides the YES community, the project should be able to recruit authors from diverse background as well (i.e., neuroscientists/engineers...) and not primarily affiliated with YES or ILAE. For this purpose, in my opinion some incentives should be created. Why should anybody with an academic background write in Wikipedia? Why an academic should "use her/his time" to write an entry in Wikipedia if it is not recognized for the advancement of her/ his career? In the past, we thought to have some plaques that the ILAE could give to authors of the Wikipedia project as a statement of recognition. I must admit that up to now this approach has not been very successful: authors wrote their entry without even requesting the plaque. I just raise this point for the new leadership to explore new ways in this direction.

3- Recruit reviewers:

This is a very challenging part of the project. This is due to two aspects: 1- senior academics are still not happy to collaborate on Wikipedia aspects. Therefore, even if they agree to review an entry, this takes a huge amount of time and very often reviewers drop the process and become unavailable. Some innovative thoughts are needed so to increase the will of senior academicians to be involved. 2- The review process itself. Up to now, to comply with a formal reviewer process, the entry is being written in word as reviewers are familiar with word environment and not the Wikipedia environment. This makes the whole process extremely slow and lengthy. To deal with this issue, in my opinion, it should be promoted that the review process will be done online into Wikipedia itself.

4- Organization of courses on how to work into the Wikipedia Environment:

This is an important aspect dealing with spreading the knowledge on how to work into Wikipedia to the ILAE community. If both authors and reviewers are familiar with the Wikipedia environment, the whole workflow of the process will be easier. Besides the workshop that we launched in Bangkok (I think that the setting of workshop should be continued at the incoming ILAE sponsored meeting), I tried to organize formal internet-based Wikipedia courses for ILAE members possibly using a sort of VIREPA platform. I tried to enroll WikiEdu into this, but I was not successful. Maybe this was due to a sort of a conflict that this idea had with the vision and aims of WikiEdu. I think that the organization of courses on Wikipedia Environment for ILAE members should be further explored and organized.

5- Create an ILAE Wikipedia Epilepsy Project Community:

The seeds of this idea have been already spread, but this concept should be further developed. The basic idea is to create a sense of community into the ILAE world for those participating at the project. They should feel part of something important. Therefore, in my opinion, exclusive events for the community should be planned, organized, and advertised. People should get the idea that by being part of the ILAE Wikipedia Epilepsy project community is good, fun and help them to advance their careers. We thought of having social activities at ILAE meeting restricted to the community; restricted activities with senior ILAE officials, etc. In my vision, the impact of social media will boost this concept. We started to explore this with the YES and that's why we appointed a social media editor and an akatons editor into the board.

Submitted by Nicola Maggio

ILAE Wikipedia Epilepsy Project – New Leadership

Work done by the new leadership so far:

Even though Wikipedia can be edited by anybody, Wikipedia follows strict policies and norms to ensure quality of its articles. Writing on Wikipedia follows the same principles that are used in academic articles, except for the fact that it is important to reference each sentence by citing a reliable source. Upgrading the epilepsy related information on Wikipedia would therefore involve systematic involvement both from the epilepsy professionals as well as the Wikipedians. This would involve mentors and reviewers from either side on one hand and on the other hand a community who actively take involvement in updating the articles. The new leadership under Diptanshu Das (Editor in Chief) and Nandan Yardi (Deputy Editor) has tried to take a structured approach to ensure community participation into the project.

Organising resources

The **project information** has been organised under various tabs by Diptanshu Das at https://en.wikipedia.org/wiki/Wikipedia:ILAE_Wikipedia_Project/About

This includes **learning resources** that in less than half an hour can easily familiarise interested individuals with Wikipedia norms and policies:

https://en.wikipedia.org/wiki/Wikipedia:ILAE_Wikipedia_Project/Training_materials

The **levels of involvement** have been systematically defined into various categories
https://en.wikipedia.org/wiki/Wikipedia:ILAE_Wikipedia_Project/Apply_to_Join

Furthermore, a **Code of Conduct** has been prepared to ensure healthy community participation
https://en.wikipedia.org/wiki/Wikipedia:ILAE_Wikipedia_Project/Code_of_Conduct

The project pages list the things that need to be done and are designed to track the updates.

Organising scope of involvement

Diptanshu Das has identified more than 200 existing articles to lie within the purview of the project. The articles have been tagged under WikiProject Epilepsy to ease the work. Details at:
https://en.wikipedia.org/wiki/Wikipedia:ILAE_Wikipedia_Project/Articles

Work with respect to articles

- Plagiarism check was run by Nandan Yardi on a set of 8 draft articles prepared by YES authors under the previous leadership. However, most of them were found to be in requirement of significant paraphrasing before they can be integrated into Wikipedia. The authors have been contacted and invited to work to improve the draft articles.
- A set of 27 articles on important epilepsy related topics have been identified by Nandan Yardi to be worked upon in the first phase.
- The draft article on Evoked potentials by Analia Pastrana, an YES contributor guided by Atul Maheshwari, is currently being updated.
- Tomson T, Battino D, Bromley R, Kochen S, Meador K, Pennell P, Thomas SV. Management of epilepsy in pregnancy: a report from the International League Against Epilepsy Task Force on Women and Pregnancy. *Epileptic Disord.* 2019 Dec 1;21(6):497-517. doi: 10.1684/epd.2019.1105. PMID: 31782407. The license of this important report from the ILAE in liaison with Dr Tobjorn Tomson has been updated so that the contents can be merged into Wikipedia as relevant.
- Inputs on existing Wikipedia articles like https://en.wikipedia.org/wiki/Evoked_potential by experts like Neelan Pillay, Emory University and Charles M. Epstein, Cumming School of Medicine, University of Calgary have been sought.
- https://en.wikipedia.org/wiki/Anti-IgLON5_disease and https://en.wikipedia.org/wiki/Epilepsy_and_driving are being updated by Nandan Yardi.
- https://en.wikipedia.org/wiki/Epileptic_Disorders has been significantly updated by Diptanshu Das based on the work by Fabio Nascimento (Current Social Media Editor, Epileptic Disorders) on the initiative of Sandor Beniczky (Editor-in-Chief, Epileptic Disorders).

Team building and active participation

- A liaison with the YES team has been developed so that the YES authors can be urged to contribute to the project.

- Various experts on epilepsy subjects are being reached out to and their expertise is being sought to review the existing articles within the scope of the project. Their inputs would be listed on the talk page of the article so that the interested contributors can make the necessary changes to upgrade the article in a manner identical to that followed in case of academic journals.
- Wikipedians like Amin Azzam, Adjunct Professor, UC Berkeley - UCSF Joint Medical Program, University of California along with Diptanshu Das have shown active participation in shaping strategies and training materials.

Work in progress

- Inviting volunteers to participate as editors/contributors for both new and existing articles and to form a community enthusiastic about epilepsy related topics.
- Forming a community of active epilepsy contributors (editors) to carry on the task of developing and improving epilepsy related articles on Wikipedia.
- Forming a body of peer reviewers (selected in the way it is done for academic journals) and devising a way to peer review existing epilepsy related articles on Wikipedia.
- Contacting experts from various ILAE commissions and chapters and form a body of subject matter experts for the project. They will review the articles with respect to the scientific accuracy and academic contents of the articles and suggest changes to be made to the articles. Based on the inputs the contributors will make the changes and the articles would be re-evaluated thereafter.

Future plans

The plans and objectives for the upcoming year are as follows:

- To work on upgrading a list of 27 important existing articles within the scope of the project, as identified by Nandan Yardi (list can be seen on ILAE website) <https://www.ilae.org/journals/ilae-wikipedia>
- Simultaneous work will go on with respect to these and other articles identified.
- Building a community of epilepsy professionals eager to improve the quality of information available to the people on epilepsy related subjects.
- To improve the understanding of Wikipedia and its dynamics among the academic community curated by the ILAE.
- To get the project and its contributors recognized as a formal user-group by Affiliations Committee [https://meta.wikimedia.org/wiki/Affiliations Committee](https://meta.wikimedia.org/wiki/Affiliations_Committee) of Wikimedia Foundation.

Submitted by Diptanshu Das MD, Editor in Chief and Nandan Yardi MD FAES, Deputy Editor