

# Wikipedia Epilepsy Project

# 2021 Annual Report

#### **Members**

Diptanshu Das (India), editor-in-chief Nicola Maggio (Israel), former editor-in-chief Nandan Yardi, deputy editor Amin Azzam (USA), Wikipedian Marium Umme Kulsum (India), Wikipedian Nadia Khan (India) Christos Lisgaras (USA) Atul Maheshwari (USA)

## Background

- Wikipedia has a huge readership, especially with respect to health-related information.
  - For example, Wikipedia article Epilepsy has been viewed 7,12,511 times in 2021 with an average of about 2000 hits daily, check Page view report for Wikipedia article 'Epilepsy' for 2021
  - Wikipedia article Seizure has been viewed 3,90, 813 times in 2021 with an average of more than 1000 hits daily, check Page view report for Wikipedia article 'Seizure' for 2021
  - Wikipedia article Febrile seizure has been viewed 1,14,368 times in 2021, check
     Page view report for Wikipedia article 'Febrile seizure' for 2021
- Both professionals, as well as lay people, read health information on Wikipedia and it is important to ensure the quality of such information. Masukume, G; Kipersztok, L; Das, D; Shafee, TM; Laurent, MR; Heilman, JM (November 2016). "Medical journals and Wikipedia: a global health matter". The Lancet Global Health. 4 (11): e791. doi:10.1016/S2214-109X(16)30254-6. PMID 27765289
- 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.

#### **Context Before 2021**

- More than 200 articles tagged under the scope of the project (details at https://en.wikipedia.org/wiki/Wikipedia:ILAE Wikipedia Project/Articles)
- Project page with relevant training materials and instructions created at https://en.wikipedia.org/wiki/Wikipedia:ILAE Wikipedia Project/About
- A frame of action was created for the project

### **Developments in 2021**

- Top 30 articles identified for editing on a priority basis
- Workflow of the project defined
  - o For the specified articles preparation of action items for improvisation
  - Identifying contributors who could execute the requisite changes for the given articles
  - Writing to peer-reviewers with subject-matter expertise and requesting them to review the article with respect to the scientific content
  - Incorporating the suggested changes in a manner that is done for a journal article
  - Evaluate if the Wikipedia article can be published as a review article in an academic journal
- The creation of the position of a Wikipedian-in-Residence and hiring of Marium Umme Kulsum for the same
  - To make the requisite changes to the Wikipedia articles within the scope of the project
  - To work out a to-do list for the given set of articles
  - To coordinate with the peer reviewers and get the articles reviewed
  - o To collaborate with the team of contributors and to make things happen
  - To oversee the strategy and progress of the project
  - o Educating others on the norms of Wikipedia editing
- Creation of an internship project
  - To get young contributors involved in improvisation of epilepsy-related articles on Wikipedia
  - o To familiarise them with the norms of Wikipedia editing
  - To promote collaborative team contributions for greater good
- Creation of a structured project to track contributions by participants
  - https://outreachdashboard.wmflabs.org/courses/International\_League\_Against\_ Epilepsy/ILAE\_Wikipedia\_Epilepsy\_Project/home
  - The unified dashboard summarises the edits made within the scope of the project. It gives a list of articles, edits made by respective contributors, and a detailed and transparent tracking system for the same.
- Overall contributions:
  - Over 30 Articles Edited
  - Over 800 Total Edits were made to the given articles
  - Over 45 Editors participated actively in the project
  - Over 25 Editors completed training modules to understand the norms of Wikipedia editing
  - Over 36,000 Words were added to the articles within the scope of the project
  - Over 300 References Added to the given articles
  - The Articles were viewed more than 760K times
- Articles edited:

- Details of articles edited can be found at <a href="https://outreachdashboard.wmflabs.org/courses/International League Against Epilepsy/ILAE Wikipedia Epilepsy Project/articles/edited">https://outreachdashboard.wmflabs.org/courses/International League Against Epilepsy/ILAE Wikipedia Epilepsy Project/articles/edited</a>. Current version with authorship highlighting and cumulative changes visible using the Assessment tools on the right of the page. Clicking on the 'article development' link just below the article name would give the timeline of expansion of the given articles
   Wikipedia article Febrile seizure
  - The article was completely revamped by Drs. Peter and Carol Camfield.
     The contributions (made offline by them) were later updated to the Wikipedia article by Marium Umme Kulsum.
  - The Camfields shared the IWK Health Center Research Award in 2005. Peter Camfield was the Bellagio Scholar of the Rockefeller Foundation in 2002, recipient of the Penfield Award of the Canadian League Against Epilepsy in 2003, and of the Epilepsy Canada Pioneer Award in 2003 and was a member of the ILAE Commission on Outcome Measurement 1995-1997.
  - Thus the article marked the engagement of subject-matter experts from ILAE into the scope of this project.
  - Overall changes made to the article
     https://en.wikipedia.org/w/index.php?title=Febrile\_seizure&type=revisio\_n&diff=1066880022&oldid=1057709267
  - The article was viewed 1,14,368 times in 2021 https://pageviews.wmcloud.org/?project=en.wikipedia.org&platform=all-access&agent=user&redirects=0&start=2021-01-01&end=2021-12-31&pages=Febrile seizure
- o Wikipedia article Early myoclonic encephalopathy
  - Over 2000 words and 30 references added by Marium Umme Kulsum.
     Some more contributions to the article were made by Akshita Roy, a medical student and an intern under the project.
  - Overall changes made to the article
     https://en.wikipedia.org/w/index.php?title=Early myoclonic encephalop
     athy&type=revision&diff=1060476924&oldid=1055565587
- Wikipedia article Childhood absence epilepsy
  - Over 1800 words and 35 references added by Marium Umme Kulsum.
  - Overall changes made to the article
     https://en.wikipedia.org/w/index.php?title=Childhood absence epilepsy
     &type=revision&diff=1063566638&oldid=950623681

Submitted by Dr. Diptanshu Das MD, editor-in-chief, and Dr. Nandan Yardi MD FAES, deputy editor