

# ABS 105

## What do people with neurofibromatosis look for? - Analysis over 250.000 visits to a blog of medical information

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**Background:** Online searching for medical information is a common behavior, especially among people with rare diseases, which are looking for health professionals and treatment. Neurofibromatosis (NF) are rare diseases, with great diversity of signs, symptoms and clinical complexity, with only a few health professionals with adequate knowledge for its diagnosis and follow-up. To provide information about NF, based on scientific evidence, we have created a blog (<http://amanf.org.br/blog/>) in Portuguese. It has been active since 2015 and has received around 15 thousand visitors per month.

**Purpose:** To evaluate the profile of over 262,679 visitation sessions to this NF blog during 30 months (from 5/8/2015 to 11/17/2017).

**Methods:** Visitors were studied through Blogger's analysis system and Google Analytics to identify the most sought-after topics among the 405 already published, as well as some user's characteristics.

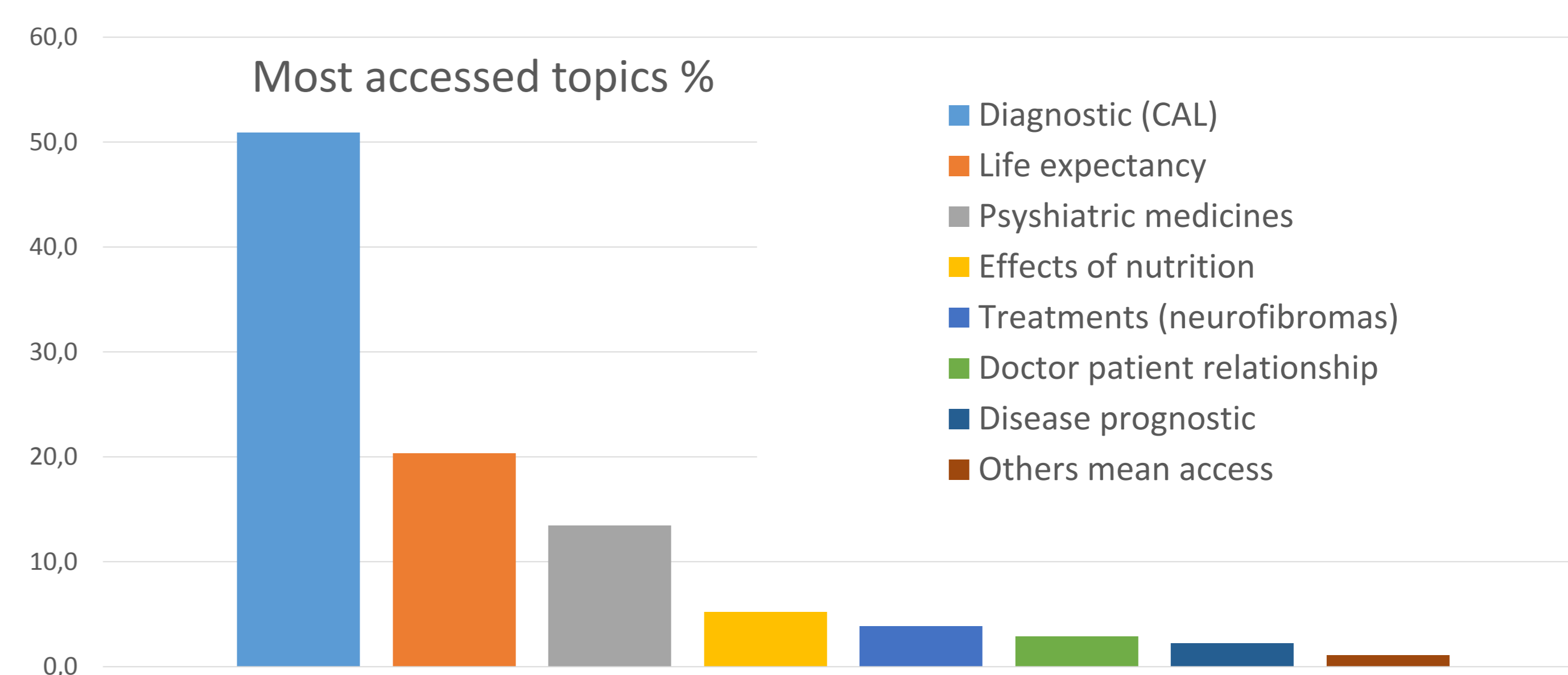
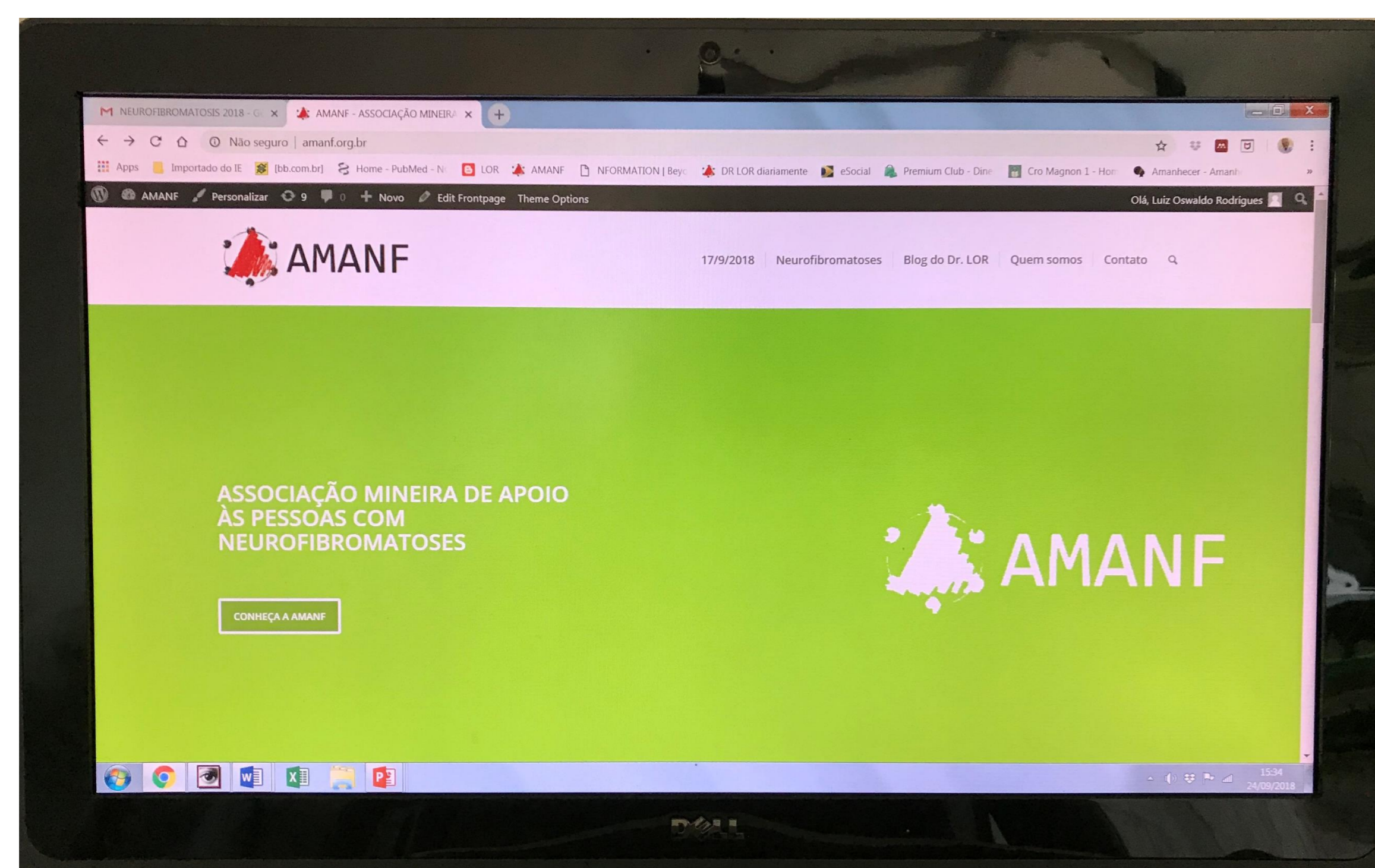
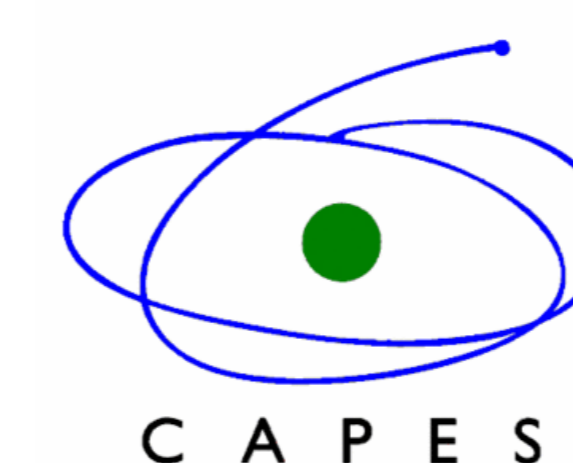


Figure 1 – Top visited topics (percentage) among the 405 themes posted from 5/8/2015 to 11/7/2017.

**Results:** The majority of visits have been of people located in Brazil (83%), using Portuguese Language (92%) in smartphones (54%), accessed from São Paulo (10.8%), Belo Horizonte (9.7%) and Rio de Janeiro (5.8%). The most sought-after topics were information on Neurofibromatosis type 1 (NF1 – OMIM # 162200), especially focused on diagnosis (50.9%) and life expectancy (20.3%). Other topics of interest have been: psychiatric medicines (13.5%), nutritional effects (5.2%), treatment for neurofibromas (3.9%), doctor-patient relationship (2.9%) and disease prognostic (2.3%). The mean frequency of all other topics accessed was 1.1%. (Figure 1). Most of the access occurred using Android (44%) and IOS (10%), indicating that half of the people have used cell phones to access the website. Average duration of visits was 3 minutes due to a) lack of interest in most of the published topics; or b) superficial reading of most subjects; or c) technical language barrier due to poor formal instruction of internet users; or d) the combination of all causes previously mentioned .

**Conclusion:** This blog with scientific medical information on neurofibromatosis has attracted thousands of visitors, especially interested in the diagnosis of the disease. Short reading time suggests the need to review and simplify selection of topics of greatest interest.

*Acknowledgement: To Ana de Oliveira Rodrigues for her inspiration and supervising in our initial blog creation.*



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