



Programme of community action in the field of health (2008-2013)



**European registry and network for  
Intoxication type Metabolic Diseases (E-IMD)  
Contract no: 2010 12 01**

Deliverable 02: Website and electronic newsletter  
June 2014

## Description of the deliverable

Up-to-date information of E-IMD, clinician and patient information will be made available on the website. The website will be updated every four months and at the end of the project with the new consensus care guidelines in patients own language.

## EXECUTIVE SUMMARY

The website is available at [www.e-imd.org](http://www.e-imd.org). Information brochures for patients, parents, and healthcare professionals have been developed. Brochures for healthcare professionals are in English, whereas brochures for patients and parents have been translated into 11 languages. Newsletters are sent regularly and can be viewed in the news section of the website. The website has achieved good coverage and accesses have been made worldwide. About 200 accesses to the website per month have been documented on average from January 2012 to April 2014. On average, users stayed 6-7 minutes on the website. The website has been an important instrument for patients and external healthcare professionals to contact the network. The main enquiries are related to the location of an expert in a particular country, advice on care / treatment, future research. All enquiries are answered in a timely manner, to the greatest extent possible, in the individuals own language. The google search engine lists the E-IMD website on the first page when typing "organic acidurias" or "urea cycle disorder".

# 1. THE WEBSITE

www.e-imd.org



## 1.1. DEVELOPMENT

The CHU

## 1.2. WEBSITE EVALUATION REPORT

As part of the project a website was developed which had 3 primary functions:

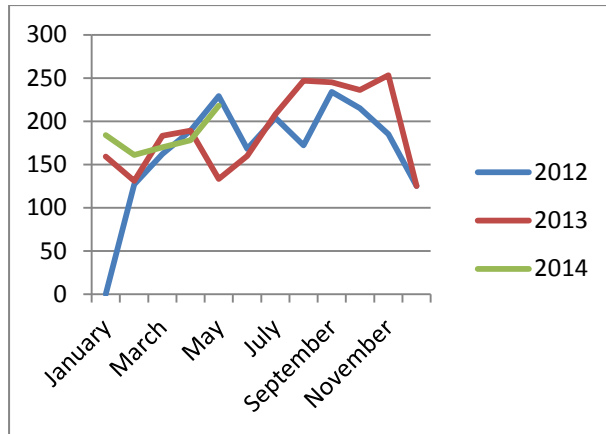
- ▶ To showcase E-IMD and what it is doing – this can also be looked upon as an ‘on-line’ brochure.
- ▶ Helping people to gain a better understanding of OAD and UCD and to enable contact with E-IMD.
- ▶ To ensure that the E-IMD website is easily found by promoting it through as many media as possible.

To date the website has achieved a wide area of coverage and accesses have been made from as far north as Honningsvåg (North Cape), Norway to Tierra Del Fuego (Cape Horn), South America to Hawaii in the west to Japan in the East.

The statistics from the website during the January 2012 to April 2014 are interesting and we have looked at the

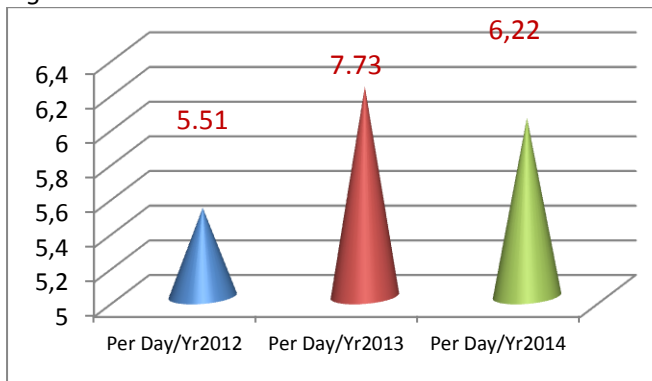
- ▶ Number of accesses per day
- ▶ Total number of true accesses during the period (accesses who have stayed on the site for longer than 10 seconds)
- ▶ Number of guides downloaded by disease group
- ▶ Number of downloads for younger people

Figure 8



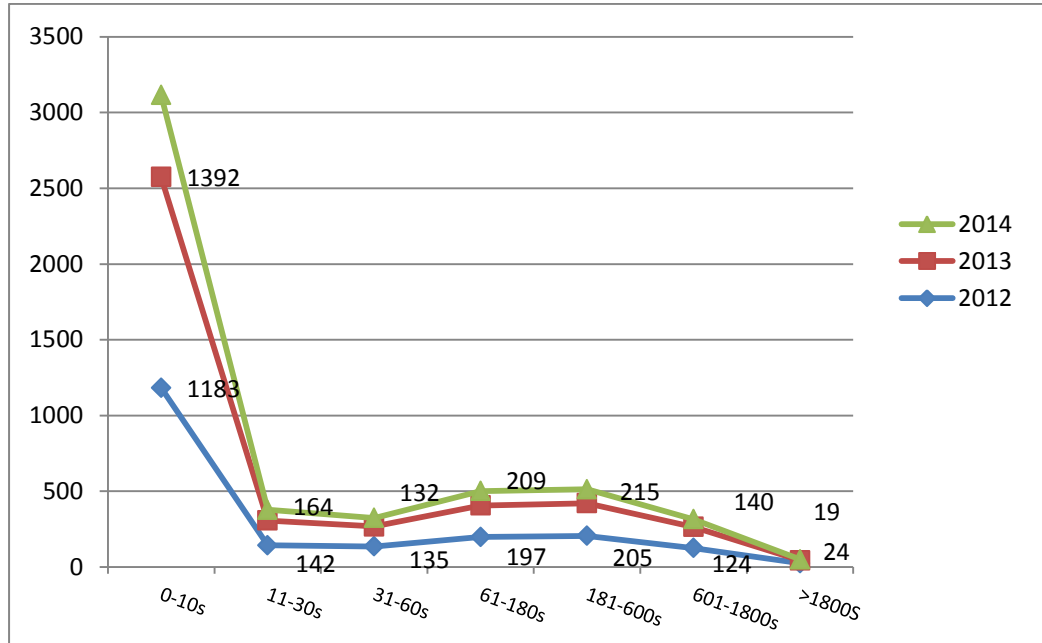
The average accesses to the website were looked at and comparisons made based on a per day/calendar year and per day/working day year for 2012, 2013 and the first 4 months of 2014.

Figure 9

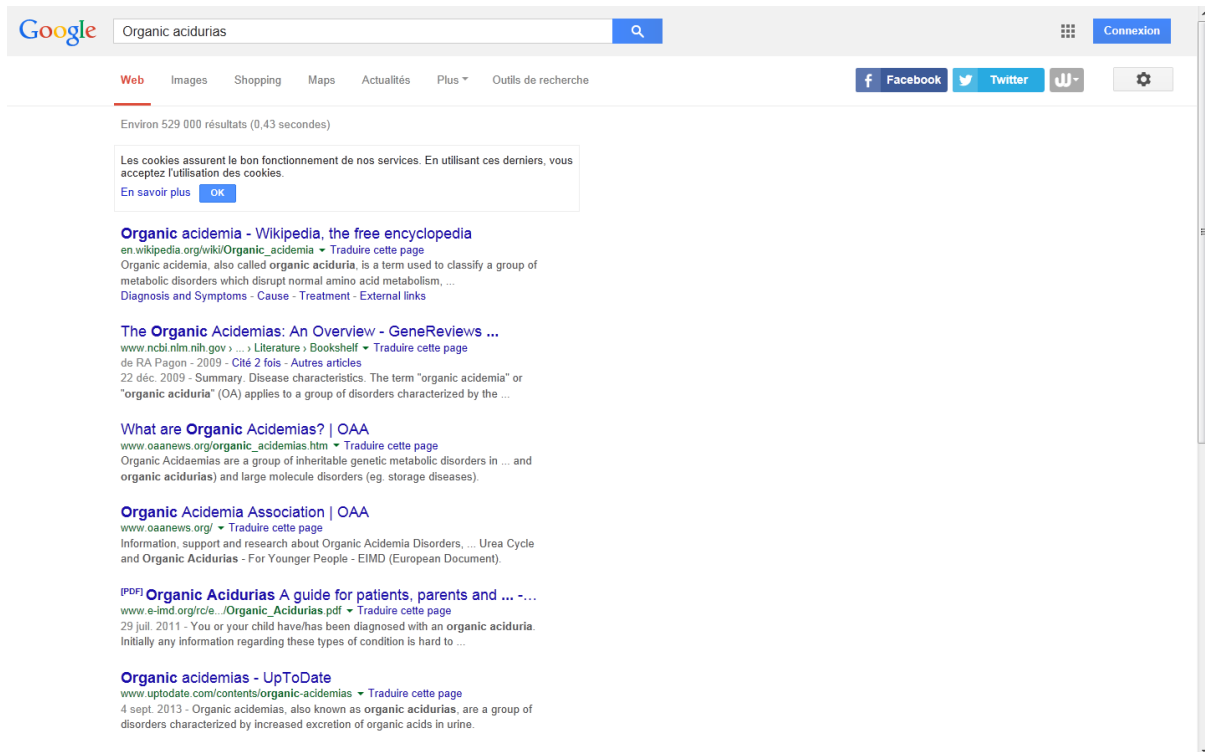


From these evaluations of access made to E-IMD website we were able to deduce the amount of time that users stayed on the various pages available to them.

Figure 10



The google search engine is efficient and E-IMD is on the first page when typing “organic aciduria” or “urea cycle disorder”.



In order to improve access to the E-IMD website the project (through Climb) have set up Facebook and Twitter accounts to enable the rapid dissemination of information and to reach families and patients more quickly.