Methods

Data was collected by Facebook Insights and Google analytics. Microsoft Excel was used for data analysis and graph representation. Time range. FB demographic data cumulative until 31st Dec 2019; Orphanet website's demographic data 1st Jan 2018 - 31st Dec 2019; editorial strategy 1st Sept 2018 - 31st Dec 2019; Facebook and Orphanet site’s growth 1st March 2018 - 31st Dec 2019.

Facebook posts and website’s users analysis. N = 5 pairs of posts were chosen and each of them was assigned to one of the two groups, with or without a link to Orphanet respectively. Each selected pair shared the number of Facebook users. The website's user number was collected according to the date of publication of each post, the time interval ranging from 1st Sept 2018 to 31st Dec 2019.

The audience covered a wide range of people (aged 18 - >65 years), with a prevalence in the age range of 25-54 years for the site users, and 35-44 years for the FACEBOOK fans (Fig. 2). These results are in line with the average age of the majority of worldwide FB users, as shown by We are Social’s Digital Report 2020.

Although the majority of our FB fans were Italian, altogether they are citizens of 10 different countries, differently from the Orphanet website users, which virtually all are Italian, taking advantage from the database translation in their own language.

The effort to broaden our audience was evaluated on the users’ response to six main topics of the posts: 1. rare disease day; 2. patients, empowerment and storytelling; 3. Orphanet news; 4. institutions and policy-making; 5. research, scientific findings and articles, innovations; 6. events, conferences, education. Not surprisingly, the posts with major engagement cover most published categories, including patients and storytelling (40%) and research (24%), as shown in figure 3.

In 2019, the posts referring to the Orphanet site reached 253,512 people, compared to 8,095 fans in 2018. This result well compares with the increased number of daily Orphanet users, whenever posts displayed a link to the website (Table 1).

Results

The majority of our FACEBOOK fans and Orphanet users were female (Fig. 1). The audience covered a wide range of people (aged 18 - >65 years), with a prevalence in the age range of 25-54 years for the site users, and 35-44 years for the FACEBOOK fans (Fig. 2). These results are in line with the average age of the majority of worldwide FB users, as shown by We are Social’s Digital Report 2020.

Although the majority of our FB fans were Italian, altogether they are citizens of 10 different countries, differently from the Orphanet website users, which virtually all are Italian, taking advantage from the database translation in their own language.

Conclusion

We cannot exclude that the views on the Orphanet site are not all attributable to the FB posts. With this limit in mind, the present results support us in:

- Creating a large community promoting Orphanet as a channel of certified and inside information in rare diseases;
- Deepening our analysis, in order to study the crosstalk between the social network growth and the Orphanet website success;
- Submitting the users a survey, to better understand their requirements and preferences.

Acknowledgement

The Orphanet team at INSERM (France) has provided us with data of the Orphanet-Italy website.