



ASOCIAȚIA GAUCHER ROMÂNIA

ACTIVITY REPORT 2018

April 2018

1. Registration of the **Romanian Gaucher Association (AGR)** as an informal group.
2. Organization of a photo competition through the Facebook Group InfoGaucher - patients with Gaucher disease in Romania participated

May 2018

3. Organization of the Workshop "**Why us?**" with the occasion of the patients with Gaucher disease meeting in Cluj-Napoca
4. Marking 20 years of existence of the **Romanian Foundation for Lysosomal Diseases (FRBL)** by granting diplomas.

June-July 2018

5. Submission of the documents for the establishment of the Gaucher Romanian Association
6. Participation to the **Workshop on the European Rare Diseases Network** organized in Zalau by the **National Alliance for Rare Diseases Romania (ANBRaRo)**, July 14-15

September 2018

7. Presentation of "**Rare Disease Support Groups**" at the **Rare Disease Case Management Workshop** organized by ANBRaRo September 29-30, Cluj-Napoca
8. Participation in the Zalau **Semi-marathon** organized by Runners Club, Zalau City Hall and ANBRaRO, September 29

October 2018

9. Registration as a legal entity of Gaucher Romania, October 1
10. Participation to the event organized by **Vaincre les Maladies Lysosomales (VML)** France - "**Lysosome Walk**" by registering walks in Cluj, Oradea
11. Meeting in Bucharest with Professor Ari Zimran (Israel), international expert on Gaucher disease - collaboration
12. Participation at the international meeting in Riga of the **International Gaucher Alliance**, 15-16 October
13. Creation and promotion of the site www.infogaucher.ro as the first Romanian site exclusively dedicated to Gaucher disease, site for physicians and patients
14. Creation of the **Facebook page** of the Gaucher Association Romania
15. Participation at the **Meeting of adult patients with lysosomal diseases** in Paris
16. Participation at the **Organizational Development Course** in Zalau, 28-30 October, organized by ANBRaRo

17. Active participation in Zalau to working-sessions on the **Care guide for patients with Gaucher disease** at the initiative (ANBRaRo), October 26-27

November 2018

18. Demand for the affiliation of AGR to ANBRaRo

19. Developing the "**Integrated Care Guide for Gaucher Disease Patients**"

December 2018

20. Participation at the **EUROPLAN** conference in Bucharest organized by ANBRaRo, 6-7 December 2018

21. Participation at the Sanofi-Genzyme meeting for patients' representatives, December 10, Amsterdam (**Gaucher Patient Advisory Board**)

22. Proposal of the project "**I want to know! - making connections, enabling information and education on Gaucher disease in Romania**" - submitted to the PAL Awards competition

Weekly activities during the year 2018

23. Consistently communication relevant for the patients in the field of Gaucher disease (IGA Newsletter, articles, news), translation and spread-up of materials, information on Facebook group InfoGaucher (74 people per group) during the year

24. Keeping in touch with patients, organizing surveys on their needs through group or personal discussions

25. Support of some patients to perform the necessary laboratory analyzes in the management of Gaucher disease (donations)

Done today, 5 March 2019, by

Oana Topan

President of Romanian Gaucher Association

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