



ASOCIAȚIA GAUCHER ROMÂNIA

ROMANIAN GAUCHER ASSOCIATION

ACTIVITY REPORT

January 2019

1. Participation at the **National Day of Gaucher Disease** in Paris, France, January 31 - February 1, experience exchange between **Vaincre les Maladies Lysosomales** and the **Romanian Gaucher Association - RGA** (a day dedicated to physicians, another to the patients with Gaucher disease - interaction and education).

February 2019

2. Participation at the **3rd EURORDIS Multi-stakeholder symposium on Improving Access to Rare Diseases Therapies** in Brussels, on February 13 - 14.

3. **Social Media Awareness Campaign** on Gaucher Disease on the occasion of **Rare Disease Day 2019** by posting on the Facebook page throughout February, some essential information about Gaucher Disease. The flash information were posted with photographs received from patients with Gaucher disease or their relatives.

4. In February 2019, the **HackRare hackathon** was held in Cluj-Napoca. A member of our association was part of the team who won the 1st prize with the project «**Selling Happiness**», a virtual therapy for patients with neuromuscular diseases, a project to allow these patients a complex social interaction despite their physical limitations.

5. Presentation at the **Rare Diseases Day Conference**, in Bucharest, held by the **Romanian National Alliance for Rare Diseases - RONARD** of our working mode for the elaboration of the **Integrated Care Guide for Gaucher disease patients** in cooperation with other organizations, at the proposal of RONARD.

March 2019

6. Elaboration of a **survey** conducted in collaboration with RONARD and a medical team from University of Medicine and Pharmacy Cluj-Napoca on the quality of life for patients with Gaucher disease in Romania. The survey was submitted toward the Romanian patients.

7. Participation at the **Masterclass Patient School** in Bucharest on March 28 - 29, at the CNAS headquarters. The purpose of this seminary was the development of a constructive dialogue between the patient associations and leaders of the health authorities.

April 2019

8. Attendance at the **Gaucher Expert Summit** organized in Berlin, April 12-13. This is an annual event with the participation of several international experts, this year's theme - **Unmet needs in Gaucher disease: have they evolved?**

9. Collaboration initiated between our association and the **Asociația Noi pentru Ei – NEI**, promoting the possibility of consulting, counseling and genetic testing for patients with Gaucher disease and their families (including the possibility of testing healthy carriers), in Cluj or Bucharest.

May 2019

10. Participation to the workshop organized by **COPAC - Coalition of Patients' Organizations with Chronic Diseases (Romania) - Talk with your doctor!**, in Bucharest, on May 11, focused on the communication of the patients with different partners: physicians, media and journalists.

11. Start of the involvement in the **QUALIMED Project - Network for formulating public policies regarding the quality of services and patient safety in the health sector**, first course held in Păltiniș, May 13 - 16, 2019, by **CREST Association** in partnership with the **National Authority for Quality Management in Health - ANMCS**. Our association was accepted as beneficiary NGO following a selection, the training program being focused on areas of quality management in health, advocacy for promoting proposals for improving public policies, sustainable development, equal opportunities, non-discrimination and gender equality, communication in health.
12. Organization of the workshop **One gene, two genes** on May 16, in Cluj-Napoca with the participation of several patients and caregivers interested in the aspect of genetic transmission of Gaucher disease. The workshop was supported with medical information by a genetician from **Asociația Noi pentru Ei – NEI**.
13. Participation at the 10th edition of the **National Forum of Patients' Associations** organized by COPAC in Cluj-Napoca, May 24 - 25.

June 2019

14. Participation at the **Regional Meeting for Rare Diseases and the Gaucher Regional Meeting**, in Struga, North Macedonia, from June 7 - 9. The event was organized by **Life with Challenges** organization and brought together patients, physicians involved in the care of patients with Gaucher disease, representatives of patients organizations from the Eastern European region.
15. Participation at the workshop **Talk with your doctor!**, organized by COPAC in Cluj-Napoca on June 14, as part of a communication training campaign dedicated to patients' organizations.
16. Participation at the second course within the **QUALIMED project - Network for formulating public policies regarding the quality of services and patient safety in the health sector** in Olimp locality, June 13 – 16.

July 2019

17. Poster presented at the **13th International Congress of the European Working Group on Gaucher Disease (EWGGD)** on July 3-6, in Clermont-Ferrand (France) - **Is treatment everything that patients with Gaucher disease need? - the point of view of patients in Romania**. Our associations participant members got a scientific grant from the EWGGD organizers and thus had the opportunity to inform the international medical community about the needs, other than treatment, of patients with Gaucher disease in Romania (poster conclusions based on patients' answers to the questionnaire launched in March).

September 2019

18. Participation at the launch of the project **Increasing capacity for newly established rare diseases associations** initiated by COPAC in collaboration with RONARD on September 13, in Bucharest. The project is funded by a grant won following an international competition in the field of lysosomal diseases, **PAL Awards** (Patient Advocacy Leadership Awards).
19. Initiation of a solidary and sportive way to bring Gaucher disease to the attention of the general public by participating in competitions of a young fellow from Moldova (Suceava Fortress Marathon, FIR Marathon, Cluj EcoTrail UltraMarathon).
20. Publication of an article **Gaucher disease today – review**, in the supplement **What do we know about lysosomal diseases?** of the **Medica Academica** journal, by a member of our association, member of the European Working Group on Gaucher Disease - EWGGD.
21. Awareness in Romanian medical world by promoting our associations' objectives and areas of activity in the supplement **What do we know about lysosomal diseases?** of the **Medica Academica** journal.

October 2019

22. The **International Gaucher Day**, October 1, is being carried out in a media release with the support of RONARD and COPAC: **In Romania, less than 50% of patients living with Gaucher disease are diagnosed**. This release made possible to highlight some of the needs of patients with Gaucher disease in Romania.
23. Participation to the world-wide event organized by **Vaincre les Maladies Lysosomales - VML France - The lysosome walk** on October 7th by registering the walk from Oradea. This was the second year in which patients with Gaucher disease in Romania accepted the invitation of the French organization.
24. Inauguration of the section **My window** on the site **infogaucher.ro** with 3 stories of some patients with Gaucher disease to raise awareness on some of the aspects of life with the disease.
25. Participation in the 8th edition of the National Conference organized by **CASPA - Community of Patient Associations** on October 7, in Bucharest, with debates on the Romanian medical system and patient safety, on the involvement of patients in all stages of care, processing of personal data by patient organizations.

26. Participation at the first **General Assembly of RONARD** in Zalău, on October 24, as a member of this Alliance.

27. Participation at the first training within the project **Increasing capacity for newly established rare diseases associations** initiated by COPAC in collaboration with RONARD in Predeal, between October 25 - 27. The main theme of this first module was communication: with the physicians, with the media and with the financiers, development of new communication skills.

28. Publication of a new article in the **Medica Academica** journal, by a member of our association, member of the European Working Group on Gaucher Disease: **I encourage physicians to see the patient as a partner - about the support that physicians can bring to an association of patients with rare diseases.**

November 2019

29. Presentation of our association as a participant in **QUALIMED Project** at the **Conference SIGMED III - Visions of quality management, measurement of the effectiveness and efficiency of the processes, indicators**, on November 6-9 in Cluj-Napoca.

December 2019

30. Participation in a new working session within the **QUALIMED project**, on December 3-4, in Bucharest, the debates being centered on the development of an integrated collection tool for the information needed to monitor and evaluate public policies in the field of quality of health services.

31. Participation in Bucharest, 12 - 15 December, at the second training within the project **Increasing capacity for newly established rare diseases associations** initiated by COPAC in collaboration with RONARD. The purpose of this training was to acquire notions of health policies, about the authorization steps of medicines for rare diseases, about the role of the community health care services, the accreditation of the social and medical services.

Weekly activities during 2019

32. Consistently communication relevant for the patients in the field of Gaucher disease (IGA Newsletter, articles, news, webinars), translation and spread-up of materials, information on Facebook group InfoGaucher (86 members), on the associations' Facebook page (530 like and 541 followers) and on the Facebook InfoGaucher discussion group (86 people present) (activity throughout the year).

33. Informing patients, caregivers and physicians about the different aspects of Gaucher disease, about the activity of the association and the possibility of participating in different congresses / conferences through the website infogaucher.ro, the first and only site in Romania dedicated exclusively to Gaucher disease, a site for physicians and patients (2400 site visits worldwide, from 38 countries, 6 continents).

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

Our priority for the next year remains the empowerment of the patients through information and education. The Romanian Gaucher Association is member of the **Romanian National Alliance for Rare Diseases - RONARD** and of the **COPAC - Coalition of Patients' Organizations with Chronic Diseases (Romania)**.

Future does not just happen! We make it! (The 3rd Multi-stakeholder Symposium on Improving Access to Rare Diseases Therapies)

Done today, January 10, 2020, by

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President of the Romanian Gaucher Association



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