



ACTIVITY REPORT

of the Romanian OI Association "Fragile People" for the year 2019

I. DEPLOYED ACTIVITIES

§1. Firstly, **granting non-reimbursible financial allowances for some families**, in order to reimburse partially/fully direct or indirect expenses, such as drugs' price, recovery bills, medical devices' cost, transportation etc. incurred by OI treatment. This year the grand total of such allowances was 9.700 lei. Four persons (one adult, 3 children) benefitted from these sums. It seems that the net assets of OI families dramatically improved, as we received less applications for allowances than in last years, and for lesser sums.

§2. Secondly, **we sent sums as Christmas gifts for all OI persons in dire needs** on the occasion of Christmas 2019!

All in all, 4 families, were recipients of these gifts, that totalled 2.100 lei. We are very glad we maintained this good habit, as in all past years!

§3. The most essential activity in 2019 was the lobby done among authorities to re-authorize the domestic use of pamidronate in OI children. As of May 2019, no foreign producer of pamidronate was on the Romanian drug market (and there is no domestic producer of the drug), for unknown - probably financial - reasons. All three companies, Dr. Reddy's, Novartis and Chiesi, had withdrawn, the latter being the last one, on May 28. The inventory of pamidronate within children hospitals rapidly reached zero, by July 2019. Our association was informed about the issues one month later. We sent letters to the line authorities: Health Ministry, National Health Insurance House, National Drug Agency regarding the total lack of the drug. Additionally, we talked directly to them on 9, 10

September and on 7 October. This eventually resulted in solving the problem by December 2019. An emergency authorization was issued (normal authorization have six months duration!), and Pamifos was bought and provided to hospitals.

We have no enough words to express our gratitude to Dace, Ingunn, Ute, Lyubov Petrova. They helped us in a grave moment for OI children in our country.

Still, there is a clear need to ensure the continuity of production in Europe of bisphosphonates.

§4. We also **periodically updated our website** www.oiom.ro, with news and other useful information.

§5. Last, but not least, **we collected funds through: fiscal form 230** etc. Special thanks to all those who helped us in getting the money needed to our functioning

II. FINANCING SOURCES

1. Excedent form 2018: **34.600 lei**
2. Sums via fiscal form 230, received from fiscal authorities: **21.200 de lei**

III. BREAK-OUT OF EXPENDITURES

1. Related to OI: **11.800 lei** (see §1 and §2 above)
2. Administrative expenditures (including OIFE membership fee): **3.900 lei**
3. Bank commissions: **650 lei**

III. EXCEDENT

As of 31 December 2019, our association posted **an excedent of 39.450 lei**, which shall be used in the next year, 2020.

PRESIDENT

Cristian-Florin Dănanău, Ph. D.