



Asociația Română de
Osteogeneză Imperfectă
"Oameni Fragili"

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"Oameni Fragili"
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ACTIVITY REPORT

of the Romanian OI Association "Fragile People"

for the year 2014

I. Activities

The main achievement in 2014 has been the *introduction of telescopic rods within the OI national health programme for rare diseases*, following an almost two-years long period of lobby activities among authorities from our part.

In this way, both the drug component and orthopedic component of the OI treatment protocol are entirely financed from the state budget for healthcare. According to official information received from National Health Insurance House (the authority in charge with the implementation of the healthcare services) in 2014:

- 29 children received drug treatment (pamidronate infusions). The actual budgetary expenses were 18.950 lei;
- 9 children received telescopic rods. The actual budgetary expenses were 247.000 lei;

The national programme for rare diseases – osteogenesis imperfecta section is currently implemented within 2 children's hospitals in Bucharest and one county hospital in Târgu-Mureș (Mureș county). Also, pamidronate infusions are performed in other general or children hospitals all around Romania, but the corresponding expenses are not known and are not included in the above figures. We hope that in 2015 more and more children will benefit from this huge improvement of OI treatment programme;

- our association granted *non-reimbursable allowances to 4 OI children* and their families, directed to cover partially the expenses generated by OI treatment. The total amount granted was about 16.000 lei;

- *we have donated two automatic injectors* to the Children's Hospital "Marie Curie" in Bucharest. This donation was aimed at improving the quality of infusions performed on OI children, and on other patients as well. The value of this donation is 7.500 lei;

- we have sent *200 lei per family to all known OI persons (both members and non-members) in our national database, on the occasion of Christmas 2014*. All in all, 30 individuals received these sums;

- in October 2014, a representative of our association, *dr. Alexandru Ulici, honorary member, participated to the XIIth OI international conference* held in Delaware, U.S.A. In this way, our members and other interested parents benefited from updated information regarding the OI treatment applied worldwide.

Finally, one should mention that our website, *www.oiom.ro*, has been regularly updated with news, in order to reflect these activities.

II. Financing sources:

All these activities were unfolded with money obtained from:

- *membership fees* of the association's members;
- *monthly interest* from time deposits with banks;
- *sums from fiscal form 230* (2% of income tax), received via fiscal authorities;

- a single sponsorship, of **7.000 lei**, *received from the Romanian branch of Novartis Oncology* (the producer of Aredia). Many thanks to our generous friends!

It is worth mentioning that at the end of 2014, our association posted a budgetary surplus, that shall be utilized (and was!) in 2015.

It is also of interest to inform the readers of the this report that our association has 0 employees (as it also had in previous years), in order to further minimize the functioning costs. As usual, all our work has been carried out through voluntary and dedicated participation of our members.

Note: the average exchange rate of the national currency (lei) is 4,5 lei/euro.

President,
Cristian-Florin Dănănu, M.B.A.