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Organization: National Association Defeating Cystic Fibrosis (ANIFC) in
Republic of Moldova

ANNUAL REPORT



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1. CONTEXT

General Description

- Cystic fibrosis is the most common autosomal recessive monogenic disorder, caused by the disruption of chloride transport in epithelial cells, leading to the production of viscous secretions by exocrine glands. Clinically, it is characterized by multi-organ involvement with a chronic progressive course.
- The frequency of cystic fibrosis is approximately 1:4000 live births in the Caucasian population of North America and Europe, and in the countries neighboring the Republic of Moldova, it is 1:2000-2500 live births.
- The medico-social importance of this pathology is determined by the low average life expectancy and the major potential for disability starting in early childhood, as well as the major risks of an inevitably fatal prognosis due to pulmonary, gastrointestinal, and nutritional complications.

Purpose/Goals

Contributing to the increase of the average life expectancy of children with cystic fibrosis.

General objectives:

- Free access to necessary medications included in the list of reimbursed drugs. Continuous provision of necessary medications and nutritional supplements.
- Increasing access to quality medical care and promoting a multidisciplinary

approach to treatment.

Specific objectives:

- Advocacy and lobbying regarding the treatment protocol, the national program, and the inclusion of necessary medications in the list of reimbursed drugs.
- Information and fundraising campaigns for the benefit of families with children affected by cystic fibrosis.

2. BENEFICIARIES

The beneficiaries of the project are families with cystic fibrosis, including both parents and children. Currently, there are 53 such families.

3. IMPLEMENTATION

Activities and Results:

- Topics published on the website www.e-sanatate.md
- Collaboration on medical topics with Oxana Turcu, pediatrician
- Donation of medical pulse oximeters with the support of "Code Factory" company
- Participation in a meeting with CF Europe to coordinate support for the cystic fibrosis community for Ukrainian patients
- Collaboration with Olga Vacarciuc, Secretary-General of the Ombudsman, to ensure advocacy & lobbying services for including Pulmozyme in the list of reimbursed medications

- April 16, 2022 – Meeting with ANIFC members and patients on "New Generation Medications" and signing the Pulmozyme request
- April 16, 2022 – Distribution of personal packages received from Rotary Club Moldova as humanitarian aid
 - Distribution of books "Ce e bine și ce-i rău" by S. Botezatu for fundraising purposes
 - Free provision of medical devices
 - Organizing transportation and accommodation logistics for a refugee family from Ukraine, as well as providing medical and financial support during their stay in Moldova
- May 3, 2022 – Correspondence requesting the examination of the file for including Pulmozyme in the list of reimbursed medications, sent to the Ministry of Health (MS), National Health Insurance Company (CNAM), and the Agency for Medicines and Medical Devices. The request was redirected to IMSP Institute of Mother and Child and Mrs. Valentina Vîlcu (Chairperson of the MS Specialty Commission in the field of phisiopneumology)
- June 1, 2022 – Receiving a negative response from CNAM regarding the reimbursement of Dornase Alfa, citing high costs
- June 2, 2022 – Correspondence with MS regarding the restoration of access to mandatory annual investigations at the IMSP Institute of Mother and Child laboratories, with reimbursed referrals from the CF doctor
- June 17, 2022 – Affirmative support communication from IMSP Institute of Mother and Child to MS regarding the need to include Pulmozyme in the list of reimbursed medications

- October 10, 2022 – Follow-up correspondence with MS regarding the inclusion of Pulmozyme in the list of reimbursed medications
- February 16, 2023 – Follow-up correspondence with MS, CNAM, and the Agency for Medicines and Medical Devices regarding the inclusion of Pulmozyme in the list of reimbursed medications
- March 3 and 15, 2023 – Negative responses from MS and CNAM regarding the inclusion of Pulmozyme in the list of reimbursed medications, citing moderate therapeutic benefit, lack of approved mechanisms for the required nebulizers, and considerable additional costs
- April 16, 2022 – Distribution of Easter packages received from Rotary Club Moldova as humanitarian aid
- March 30, 2023 – Contacting Amaxa LTD (representative of Chiesi Pharmaceuticals GmbH Austria) for collaboration to supply Bramitob (tobramycin inhalation solution), with further actions to MS and CNAM to include this medication in the list of reimbursed drugs
- April 21, 2023 – Addressing international organizations to include Moldova in humanitarian projects for access to the Trikafta medication
- June 26, 2023 – Correspondence requesting CNAM to include Bramitob in the list of reimbursed medications
- November 29, 2023 – Correspondence to MS and CNAM
- December 2023 – Distribution of Christmas gifts for children to the Cystic Fibrosis Center received from Rotary Club Moldova as humanitarian aid
- Participation in the conference "Analysis of the fulfillment of commitments in the healthcare field and respecting public consultation procedures with civil

society in the decision-making process," organized by the Soros Foundation
Moldova

Throughout the period from January 1, 2022, to December 31, 2023, several activities were carried out:

- Renewal of the patient contact list
- Communication with association members
- Maintaining parent and patient groups with CF on social media
- Care and protection guidelines during the pandemic period.

4. MONITORING AND EVALUATION

Based on the mentioned activities, we can draw several conclusions and evaluations of the association's work:

- **Visibility and Medical Collaborations:**

The association has demonstrated active involvement in communicating health topics by publishing information on news websites. These efforts contribute to raising awareness and medical education among the public.

- **Charity Initiatives and Humanitarian Support:**

Donating medical pulse oximeters and distributing personal packages and gifts by organizations such as Rotary Club Moldova show significant involvement in charitable actions, contributing to improving the quality of life for patients.

- **Advocacy and Lobbying:**

Collaboration with Olga Vacarciuc and efforts to include Pulmozyme in the list of compensated medications indicate an active approach in promoting the interests of patients, but also facing administrative and financial obstacles in this regard.

➤ **Support for Refugees and Medical Assistance:**

The association provided logistical, medical, and financial support to a family of refugees from Ukraine, highlighting its commitment to helping communities affected by humanitarian crises.

➤ **Efforts for Access to Treatment:**

Repeated requests to health authorities for the inclusion of medications like Pulmozyme and Bramitob in the list of compensated medications show a persistent struggle to ensure patients' access to effective treatments.

➤ **Negative Responses and Challenges:**

Facing negative responses from health authorities indicates significant challenges in obtaining the necessary support for including certain medications in the list of compensated drugs, including reasons related to therapeutic benefits and associated costs.

➤ **Participation in Events and Conferences:**

Participation in conferences and events organized by the Soros Foundation Moldova indicates a continued commitment to analyzing health policies and engaging in the decision-making process at the societal level.