Leading the change by prioritising patients' needs: Effèmerides

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Purpose

Develop shared positions on specific issues between patient representatives and institutions, to push policymakers to take decisions based on the outcomes and highlights of the meetings.

Target group

Parliamentarians, technical bodies of Ministries, National and Regional Institutions, other stakeholders.

Methodology

Thematic online meetings, two for each topic, were held on the European Regulation on orphan drugs, ATMP, job inclusion for PLWRD, Serious Disabilities with the representatives of patient organizations, sector experts, public and private stakeholders, a group coordinator. The work involved identifying the existing literature and legislation, current criticalities and possible solutions, and the right interlocutors in charge of overcoming the critical issues.

Ahead of the first meeting the relevant material was disseminated; the final report shared and amended by the participants before its publication in the editorial series.

Results

The result of each table was condensed into an editorial series created ad hoc, the Effèmerides of UNIAMO, launched during the celebrations for the Rare Disease Day.

The Serious Disability position paper was used by the Minister of Labor and Social Policy for some general measures; the position on the job inclusion served to respond to the public consultation of the Ministry and led to a hearing with the technical bodies of the Ministry; the position on the European Regulation was widely shared by the participants during various webinars / conferences and meetings.

The other outcomes were presented to the competent Ministers for Health and Disability and also represented the basis for responding to public calls on individual topics.

Overall, about 40 PO representatives and 30 different stakeholder representatives participated in these meetings. In the dedicated public event the audience was about 70 people.

Conclusions

Small working groups demonstrated to be an efficient way to concretely address relevant topics thus we'll continue to hold these meetings on different relevant issues either face to face or hybrid meetings. The editorial series will become a reliable source of information and a basis for policy makers.

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