

Patients' Associations from Bulgaria Without an official patients' committee in the National Medicines Agency

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What's happening in Bulgaria

A few years ago

- The Bulgarian Drug Agency(BDA) had working groups with doctors and patients.
For example, for clinical trials.
- It was useful to us because we could observe the working process of BDA.

A few years ago

- The Ministry of Health initiated a discussion on "Pharmaceutical policy" with the participation of institutions, business and patients.

Then a consensus document has been developed, which had to be implemented in the national legislation.

For political reasons (change of the Minister of Health) there was no prolongation.

Now

- Patients do not participate in the work of BDA and in the National Council on Prices and Reimbursement.
- We have no opportunity to monitor the work of the national authorities.
- Some small patients' organizations are trying to help their patients. But this is difficult and incidental.

What are the obstacles to patient involvement?

- Incorrect and unfair work of pharma companies with patients' organizations in Bulgaria. Local managers have decided to promote a particular patient organization in Bulgaria
- This has led to:
 - tensions, high incomes of certain leaders without real activity.
 - mistrust of patients' organizations in society and institutions.

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- As a consequence, pharma companies have directed their resources to doctors' organizations, although they are in a conflict of interests.
- Also to the media - which does not produce any results.
- Results: Access to innovative medicines is disturbed.

How can we work to implement patient involvement?

- Pharma companies should help to the working patients' associations on illnesses.

For example: Novartis organizes training for patient organizations for European projects – call, rules, opportunities, grants.

- Now: Lack of initiative by patients' organizations. This has to be changed. This forum is a motivation for this.

Need: Discussion between the national authorities and patients' organizations

- We will initiate a meeting with BDA and the National Council on Prices and Reimbursement to find opportunities for early access to medicine in areas of high unmet need for severe diseases.
- We will initiate a request to the new Minister of Health to set up BDA patient committees.

Need: Discussion between institutions and patients' organizations

Patients' organizations "With you" have a high public trust and we believe that it will be resulted.

Conclusion

We are very grateful to the Active Citizenship Network because I think it could be a beginning of a good initiatives.

Bulgarian patients should have access to innovative treatments.

We must work actively for improve the patients access.



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EUROPEAN & NATIONAL MEDICINES REGULATORY SYSTEMS:

CHALLENGES FOR AN EQUITABLE, TIMELY AND SUITABLE ACCESS TO INNOVATION



Thank you

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