



# Partnership with patients organizations for a stronger collective voice



# History of the idea



**MIA - Association for health promotion and education is the oldest non-governmental organization working on health issues in R.Macedonia created in 1996. Till 2004 MIA activities were mainly focused on HIV/AIDS/STIs prevention and care for PLWHA.**

**During that period MIA led the development of the successful proposal to GFAMT, participated in UNTWG on AIDS and coordinated the civic society involvement in the development of the First National Strategic plan on HIV/AIDS. Noteworthy is MIA' successful initiative of the collaborative process between the governmental and civic society organization on healthcare issues.**

**MIA was also the national NGO representative at the UNGA Special session on HIV/AIDS, Global Business Coalition, and Global Youth Coalition on HIV/AIDS.**



# History of the idea



**Since 2005, MIA is advocating extensively on patients rights and patients safety.**

**MIA's first national research on public opinion related to patient's rights initiated the improvement of the national legislation that provides, protect and promotes patients rights.**

**In 2008 the process resulted with the Patients Rights Low and beginning of practical implementation of the patients' rights in the country.**

**Since 2009 MIA is also the promoter of the process for access to essential medicine for all.**



# Coalition



**At the end of 2010, considering the great need for public pressurizing over the relevant authorities through the media, as well as the necessity to raise the public awareness about this life-threatening situation that patients with chronic diseases face, the NGO MIA initiated the establishment of Coalition of patients' associations.**

**The aim was to act jointly and lobby for the realization of the patients' rights.**

**At the beginning, the coalition was build on the network of oldest HGOs working on health issue, but in a short period of time it was composed of 17 and now of 19 patients' associations.**

# First members of the Coalition



1. Nefron
2. Zivotna iskra- Anticancer association
3. Hepta
4. Association of patients with diabetes
5. Association of people with multiple sclerosis
6. National foundation for transplantation
7. Friendship society of Turkish women - Skopje
8. Nora - patients with RA
9. Macedonian association for osteoporosis
10. Association of parents with children having cystic fibrosis
11. Association for helping the treatment for HML
12. Association for prevention of cardiac diseases – Healthy future
13. Civil association for healthy prostate
14. Borka – association for malign diseases
15. Hemofilija
16. Peperutka - Children with malignant diseases
17. Association for rare diseases
18. People living with HIV/AIDS
19. MIA – association for health promotion and education

# Coalition



**During the activities, the COALITION faced many realistic situations which required great efforts and strong lobbying, primarily because these are the first activities of this type in the country.**

**The COALITION, because of its massiveness, enabled the initiatives for certain changes to be more seriously accepted by the relevant health authorities.**

**The COALITION, managed to come to a position of negotiator with the HIF and the MoH on behalf of all patients.**

# What was succeed?



- It managed to make pressure over the government to allocate 2 million Euros in order to fill the budget of HIF which resulted in temporary stabilization of the situation, thus providing bigger availability of medicines from the positive list in the pharmacies. Unfortunately, due to the empty budget of the HIF, this problem required a sustainable approach towards the resolution.
- In cooperation with the Pharmaceutical Chamber, the COALITION managed to stop the initiative of the Government and the HIF that medicines can be issued only by pharmacists and not by technicians, which also resulted in shortening of the working hours of the pharmacies.

# What was succeed?



- **Managed a bigger availability of the medications from the positive list trough pointing out the absence/ very small number of pharmacies which have contracts with the HIF in certain towns and to make the HIF and the Bureau for medicines announce the signing of contracts with new pharmacies.**
- **Managed that the prescriptions for chronic diseases are lowered from subspecialist to specialist level, whereby the doctors of internal medicine in the hospitals throughout the country can also prescribe the medicines and the patients will not need to travel.**
- **Public awareness regarding the poor affordability of cardiovascular medicines and advocating that the HIF and the pharmaceutical sector should reduce the prices.**



# What was succeed?



- **Managed to stop the initiative of the HIF for private payment of the positive list medicines which cost up to 25 MKD, which strongly affected the budget of patients with chronic diseases, who have several diseases and low income at the same time.**
- **Impose the need for preparation of new positive list which is cleansed from old and out-of-use medicines and enriched it with efficient and modern medicines. This activated process needs to continue and to be completed!!!**
- **Managed better availability of the oral tablet therapy - transferring it from the hospital to pharmaceutical list (therapy for oncologic treatment, hepatitis C, myasthenia Gravis, urological problems and renal diseases etc.).**



# All together!

- **Leukemia** - Glivek ( Imatinib)
- **Children with cystic fibroses** - Anti MRSA therapy: Linezolid, Fusidic Acid, Teicoplanin and Anti-fungal therapy - Itraconazole and Anti-pseudomonas IV therapy Tobramycin.



**THANK YOU**

