

The power of patient organisations - the impact on national health systems during an economic crisis

Dr. Eleni Vavouraki Ilitominon

What is the impact of financial crisis in the healthcare sector

- Reductions in total expenditure have an impact on the composition of health spending, resulting in reductions in salaries, infrastructure and equipment*.
- Lowering of the public health budget has as result:
 - Less medical equipment
 - Less medical and nursing personnel
 - Access to care becomes harder for vulnerable groups

*Economou, C., Kaitelidou, D., Kentikelenis, A., Maresso, A. and Sissouras, A., 2015. The impact of the crisis on the health system and health in Greece. In Economic crisis, health systems and health in Europe: Country experience [Internet]. European Observatory on Health Systems and Policies.

Can a Patient Organisation have a significant impact on National Health System during an economic crisis?

- Our experience gives the answer: definitely, YES
- Due to their first-hand experiences and their commitment, patient organisations can have a strong impact on the health system, even during an economic crisis.

- Ilitominon has been established in October 2011, when the financial crisis in Greece had already begun.
- At that period, parents were accepted in Greek NICUs only as visitors and the visiting time was extremely short (1h/day max), meanwhile the number of breastfeeding premature babies was low.
- The ratio nursing staff: incubators was (and still is) 1:6 and the staff was feeling exhausted and discouraged; the prevailing view was that the presence of the parents in the NICUs would add another problem to their job.

 We, as parents, had experienced that separating babies from mothers has a negative impact on babies and parents' health outcomes, being also a big obstacle for breastfeeding. We realized that we had to take action to change the conditions for our babies and our families and from the very beginning we knew that we had to join forces with the health professionals in order to strengthen our voice.

We made our strategic plan focusing mainly on two major components of neonatal health care

- a) family-centered care, and
- b) promotion of breastfeeding for the premature babies.

• We collaborated with the NICUs' staff in order to investigate which NICU had the best opportunities to be the first to change its care procedures, while at the same time discovering the need for the creation of a second Breast Milk Bank in Greece.

• We started fundraising and social awareness campaigns; we communicated our message to a large population through social media, broadcast media and events to attract donators' and sponsors' interest.





 People of all ages all over the country worked voluntary with enthusiasm and made incubator covers, blankets, and knitted clothes needed for family-centred care in NICUs





In November 2016, after a two-year effort and in collaboration with the health professionals and EFCNI, we succeeded to introduce the Family and Infant Neurodevelopmental Education Programme (FINE) in Greece. The staff of the Neonatal Department of Helena Venizelou hospital in Athens was trained by invited experts from UK and has taken the first pioneering steps to accept parents as partners for their babies care.









FINE PROGRAMME IN GREECE 3 TRAINERS, 40 PARTICIPANTS

- We strongly believed in it
- Hospital staff and Ilitominon trust and respect each other and they worked as team
- EFCNI gave us great encouragement and really helped us to overcome obstacles
- All of us, including sponsors, were creative and flexible to find solutions, even when problems seemed to be unsolved

Health professionals' feedback

"In spite of the financial crisis healthcare workers in the unit are happier since they have a new plan to work with parents and they changed their attitude towards them.

The feedback we get from parents is very rewarding for us. We feel that parents are less stressed and when the babies are ready to go home they are happy and of course mothers breastfeed and feel confident to take the baby home. Through communication with parents, we even more feel the need to improve the establishment of FINE Program in the NICU. The beginning is hard but once you start you never stop to work with the parents for the wellbeing of the babies and their families."

Dr. Margarita Tzaki DIRECTOR - NEONATOLOGY DEPARTMENT - NICU /

This is our reward

The first 24/7 open NICU in Greece.

The Helena Venizelou Hospital has changed the care procedures for premature babies in our country.







 From then on, one by one, the NICUs of the country have taken steps towards implementing a more family-centered developmental care and they recognise the support and positive contribution of llitominon to this change.

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Human Milk Bank in Thessaloniki

 A month ago, our fundraising campaign for the establishment of the first Human Milk Bank in Thessaloniki has achieved its goal. Thanks to the contributions of private and corporate donators, such as the Trans Adriatic Pipeline, the Hippocrateion General Hospital of Thessaloniki acquired the equipment necessary for a Human Milk Bank.



Mission impossible?

 In both cases, we had the maximum and best result with less money and in the middle of the worst economic crisis that we've had ever experienced we've proved that patient organizations can have an empowering role in the lives of not only the patients but the whole community as well.



Mission impossible?

 Patient Organisations face many challenges when trying to achieve their goals and they need all of you as partners in order to make their mission possible.



Our Mission Is Possible

 "They (Patient Organisations), as the whole of civil society, should be (seen as) the glue that binds public and private activity together in such a way as to strengthen the common good."*

*World Economic Forum, The Future Role of Civil Society, (2013).