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"BE A LIFE DONOR": CAMPAIGN FOR ORGAN DONATION

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Abstract:

This case study investigates the "Breath Unlimited" campaign, a marketing action designed to promote awareness about Cystic Fibrosis, a rare genetic disease. The campaign was created in Greece and was promoted throughout the country. On World Cystic Fibrosis Day the campaign culminated with the hope that their message will cross the borders. Its aim was to educate the public about the health complications of patients who struggle with Cystic Fibrosis and ultimately informing and motivating people to take action so they can help. The campaign, which was launched in 2020, was designed and carried out by the Panhellenic Association for Cystic Fibrosis in collaboration with Humane, a social enterprise that empowers people with disabilities and chronic illnesses. The main symptoms of the disorder will be briefly explained and the key aspects of the campaign will be analyzed in detail.

Resumo:

Este estudo de caso investiga a campanha "Breath Unlimited", uma ação de marketing destinada a promover a conscientização sobre a Fibrose Cística, uma doença genética rara. A campanha foi criada na Grécia e divulgada em todo o país. No Dia Mundial da Fibrose Cística, a campanha culminou com a esperança de que sua mensagem cruzasse as fronteiras. Seu objetivo era educar o público sobre as complicações de saúde dos pacientes que lutam

contra a Fibrose Cística e, finalmente, informar e motivar as pessoas a agir para que possam ajudar. A campanha, lançada em 2020, foi concebida e realizada pela Panhellenic Association for Cystic Fibrosis em colaboração com a Humane, uma empresa social que capacita pessoas com deficiência e doenças crônicas. Os principais sintomas da doença serão explicados brevemente e os principais aspectos da campanha serão analisados em detalhes.

1. INTRODUCTION

The Panhellenic Cystic Fibrosis Association (PCFA) is one of the non-profit organizations in Greece (cysticfibrosis.gr). It was founded in Athens in 1983, in order to protect and assist patients who struggle with Cystic Fibrosis (CF), a serious hereditary disease with low life expectancy and no medical cure. The organization aims to tend to the needs of registered patients regarding medical care and social welfare and additionally offers them legal protection. Moreover, the organization has an active role in resolving problems relating to the hospitalization and treatments the patients undergo as well as in informing the public about prevention actions. Lastly, they provide psychological support to the patients' families (cysticfibrosis.gr).

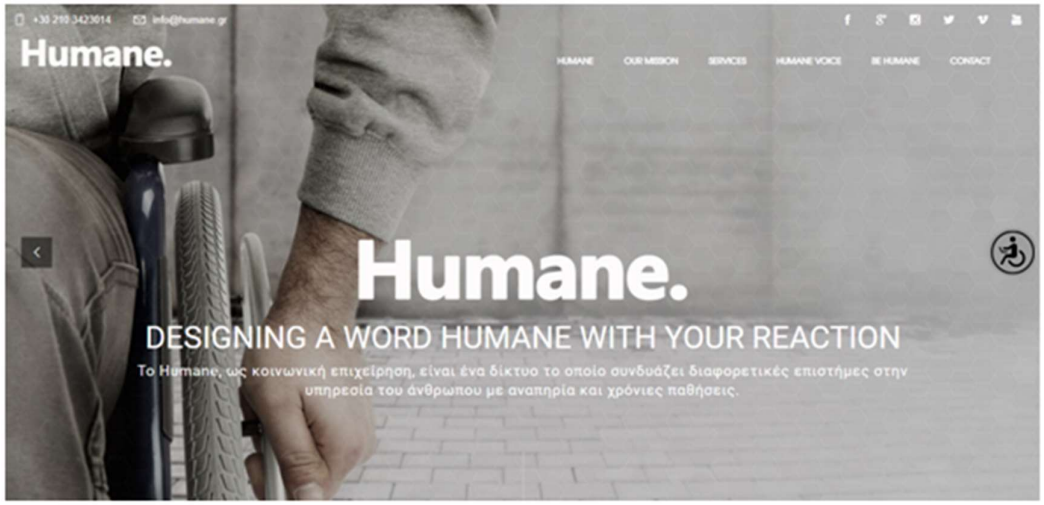
The "Parents and Guardians of Kids with CF of North Greece Association" that was founded in 1989, was merged with the PCFA 2017. The merger was carried out in order to offer a more holistic, cohesive and quality representation to the country's CF patients (cysticfibrosis.gr).

The acting chairwoman of the company, Anna Spinou, is a CF patient herself. In fact, all of the board members are either patients or parents of an affected individual, usually an underage patient. During the Covid-19 pandemic, they organized a donation of about 200 spirometers, medical instruments necessary for treatment, to patients with cystic fibrosis in Greece (dailypharmanews.gr). Throughout the years, they have also organized seminars, conferences and events in Greece or abroad. There, medical experts, psychologists and patients educate attendees about the disease and how it affects the life of sick individuals and share their knowledge and experience (greekpatient.gr).

Humane is a social enterprise that strives to empower individuals with disabilities or chronic illnesses through various projects. The start-up designs products and organizes actions with the goal of raising awareness, offering medical care, educating and helping affected individuals enter the job market (humane.gr).

One such action is the titular awarded campaign "Unlimited Breath – Be a life donor", which was organized in collaboration of the two previous organizations.

Figure 1 Initial screen from the official website of Humane



Source: [https://humane.gr], as available at 20/11/2022

2. CASE DEVELOPMENT

Facts about cystic fibrosis

Cystic fibrosis is a rare pulmonary disorder. It is characterized by salty skin and sweat and thick mucus secretions that affect many organ systems like the respiratory system (chronic bronchitis or chronic infections of the lungs, abnormal airway secretions) or the pancreas (pancreatic failure, pancreatitis). It is the most common genetic disorder in Caucasian children, and it is chronic and progressive, which means it gets worse over time and eventually leads to an early death (www.orpha.net, 2022).

The disease is caused by changes in a gene (the CFTR gene), which encodes a protein that has a regulatory role in the production of body secretions (e.g. digestive fluids, mucus). These are the mutations that lead to the formation of the thick secretions that affect the organs (in particular the lungs, liver, sweat glands, etc.), which eventually lead to organ failure (eody.gov.gr).

In Greece there are an estimated 500,000 carriers, about 700 are affected and approximately one child is born with the condition every week (if two carriers of the cystic fibrosis gene have a child, there is a 25% chance that the child will be affected) (naftemporiki.gr).

No definitive treatment exists for CF as of today. The only chance for the patients' survival is lung transplantation. However, newer treatments have greatly improved the quality of life of patients. In 1960 the majority of them passed away before 5 years of age, whereas today the average life expectancy is 35-40 years (eody.gov.gr).

Cystic Fibrosis and COVID-19

According to the numerical results of a survey by the Panhellenic Cystic Fibrosis Association conducted on 20 August, 2020, with data from 37 European countries, (cysticfibrosis.gr, 2020) we see the following: There were 18 countries that had a recorded case of a CF patient and within these countries there were 151 notified cases, with known details for only 135. The remaining 19 countries had no recorded cases. From the 135 patients, the health status of 3 is unknown, 110 patients recovered, 19 patients did not know they had contracted the disease, and 3 patients died. Overall, the male population that got sick was 53%, while the female population 43%. The study also reveals that the age groups most affected seem to be the 18-29 and 30-49 age groups, whereas the lowest incidence was in the 50+ age group (cysticfibrosis.gr).

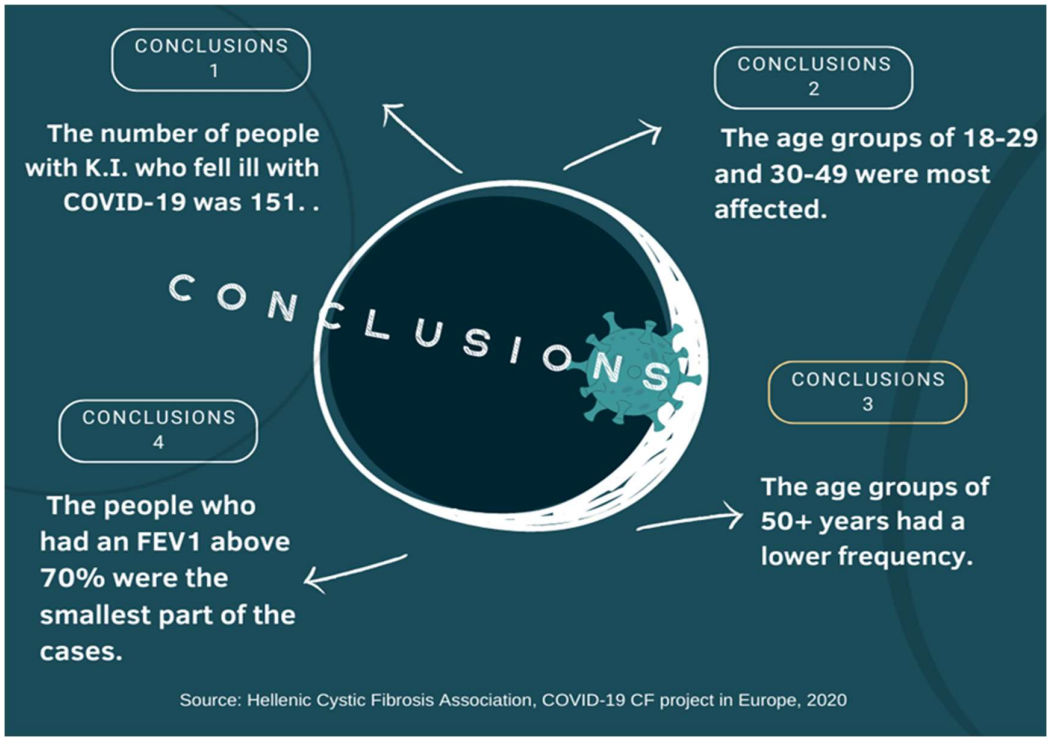


Figure 2 Conclusions about CF and COVID-19**,** (made in Canva.com)

Campaign and Awards

As mentioned before the "Breath Unlimited" campaign was designed to raise awareness about CF. The online campaign "Breath Unlimited - Be a life donor", an initiative of the PCFA in collaboration with Humane was developed under the auspices of the National Transplantation Organization in order to promote organ donation. It consisted of two parallel actions:

A. A mural on the exterior of the General State Hospital of Nikaia, depicting an actual patient with Cystic Fibrosis, Lena, who has had a successful lung transplant at the age of 18 in

Vienna, in 2016. The mural is now a key landmark of both the region and the campaign. The Hospital of Nikaia is one of the biggest hospitals in Greece and it was chosen to represent how medical facilities can assist in organ donor detection through their ICUs, the main source of potential donors. Humane designed the mural and it was created by Urban Act and artist same 84, after the hospital's enthusiastic response.

Figure 3 The mural created on Nikaia General State Hospital's wall

Source: [https://www.mononews.gr], as available at 20/11/2022

Dimitris Kontopidis, president emeritus of the *PCFA*, *Humane*'s founder and creator of the campaign, stated: "In Lena's face we impress a patient of any age and any condition who faces respiratory failure. She is wearing an oxygen mask, battling daily with the thing she's missing; her breath. She extends the tube's edge to every one of us so we can give her unlimited breath with the lung transplant. […] That's why we invite each one of you to give us a second chance at life". (mononews.gr, 2020)

Mr. Kontopidis further stated that this collaboration is proof of the necessity of practical cooperation between patients' associations and institutions that seek the empowerment of people with chronic diseases. To optimize the social impact, advocacy, empowerment, planning, care and innovation should be combined.

B. Online invitation to participate in a challenge. All citizens are invited to register themselves in the Organ Donor Registry. They then will upload their photos online (https://abilitiesdays.com/challenge/) to share their doing so.

Figure 4 Sample photos of people who participated in the BE A LIFE DONOR challenge

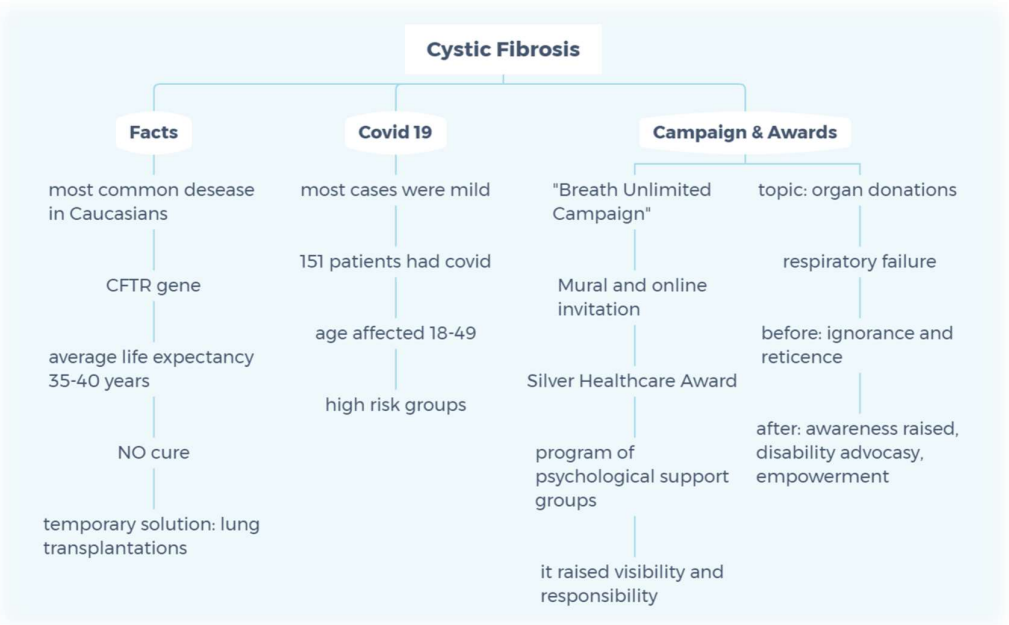
Source: [https://www.mononews.gr], as available at 20/11/2022

PCFA was awarded for its successful campaign "Unlimited Breath - Be a life donor" with the Silver Healthcare Award in the category "Patient Associations, Information/Awareness/ Prevention Activities", at the Healthcare Business Awards 2021 of Boussias and Health Daily (the largest awards organization in the healthcare sector) (mononews.gr, 2021).

During the award ceremony, Anna Spinou dedicated the award to the late PCFA Secretary General, Vasilis Palios, who fought for the Association until his last moments (iatronet.gr, 2021).

Additional Actions

In 2022, as part of the campaign, the PCFA created, for the first time, a program of psychological support groups for CF patients and their caregivers. The association's Vice President and psychiatrist, Eirini Katsini had stated that, even though revolutionary new treatments have transformed Cf into a chronic disease as opposed to a life threatening condition, new parents still go through emotions of extreme distress when they first find out that their child is diagnosed with it. The different patient profiles (treatment-excluding mutations, transplantation gone-through or not) may also lead families to feeling isolated and having very different support needs. That's why, as Ms Anna Spinou has explained: "With this action we wish to give a chance of free, much-needed support not only to [Athens] based families but also to those living [...] in secluded areas where access to mental health centers are limited or non-existent. The goal of this program is to educate, guide but also empower our patients and their careers in their management of anxiety and negative emotions that stem from the disease, but also help them reframe their lives based on new challenges and circumstances (iatronet.gr, 2022).



Source: Author's own elaboration on the basis of Lambin (1993).

3. QUESTIONS FOR DISCUSSION

Question 1. How does the life expectancy of CF patients in Greece compare to that of patients in other European countries?

In Europe the average life expectancy of CF patients is 35 to 40 years old. However, in Greece, even though the patient registry is incomplete, that number is 20 to 25 years old (cysticfibrosis.gr).

The main reasons that explain that discrepancy is the absence of the relative infrastructure and specialized care centers needed, as well as a lack of trained physicians and care staff that should comprise the multidisciplinary team tasked with caring for and attending to the very special needs of CF patients. Generally, CF as a disease is still being researched; there is no definitive cure, only alleviation treatments, and even inside medical circles there doesn't seem to exist sufficient knowledge to effectively combat the condition. The ignorance surrounding the issue combined with the shortage of funding and inadequate political prioritization exacerbate it even further (Conway et al., 2014).

Question 2. How did the Covid-19 pandemic affect CF patients and how were their needs highlighted?

Most CF patients that were infected with the Covid-19 virus saw an obvious deterioration in their health. Covid-19, which is caused by the severe acute respiratory syndrome coronavirus 2, poses a particular threat to people with compromised respiratory systems (such as CF patients) and has been proved to put their health and lives in great jeopardy (cdc.gov, 2019).

In Europe, during the initial stages of the pandemic, there were very few cases of infections in CF patients recorded, something that came as a result of their and their relatives' and healthcare providers' rigorous efforts to protect them through social distancing. Many medical centers avoided unnecessary regular hospital visits and opted instead to either conduct procedures remotely through email and phone communication or postpone them indefinitely. The European Cystic Fibrosis Society (ECFS), however, speculated that these measures will probably act negatively on patients' long-term health (thelancet.com, 2020).

Overall, the pandemic brought forward the need for additional protection and support for high-risk groups such as CF patients. What the "Breath Unlimited" campaign did was to shed light to this particular circumstance by spreading awareness about the needs of people struggling with the medical condition. Releasing the campaign during the height of the pandemic, when the situation was most severe, managed to create visibility for the patients in a critical time and encourage the public to honor their social responsibility to support people belonging to vulnerable groups.

It's also worth noting that the campaign not only managed to communicate the need for additional protection, but also offered a more proactive way of offering help. By inviting people to register as organ donors it established the notion that staying informed and aware is only one step of the process and that an active approach is also essential. According to Dimitris Kontopidis, organ donor registrations increased threefold after the launch of the campaign which, impressively, happened in the middle of a pandemic lockdown (iatronet.gr, 2021).

Question 3. What factors are responsible for the low number of organ donors in Greece? How has the campaign influenced this situation?

Greece is consistently claiming the last places in organ donations in Europe. In 2021, the country had 5 organ donors per million people when in Europe the average number is 20 donors. To put things into perspective, if a patient were to be placed in an organ waiting list in a country like Spain (that has an average of 35 donors per million people) they would have to for about six months to get a transplantation when in Greece the same patient would have to wait for 7-8 years (if they managed to survive this long) (Evlavis & Kafkia, 2018).

According to Ms. Yiouli Menoudakou, head of monitoring and coordination of the transplantation process of the National Transplant Organization (NTO), the health system's shortcomings are mainly to blame for that situation (amna.gr, 2021). Organ transplantation is an extremely complicated process that demands the coordination of many health professionals, but the lack of funding combined with the understaffed clinics and ICUs, and the absence of expert personnel devoted to recruiting organ donors and coordinating the transplantation process further exacerbates the problem.

Additionally, the ignorance that surrounds the concept of organ transplantations in Greece is also responsible for the country's disappointing performance on the matter. People's inadequate information about the process leads them to reticence and suspicion. Indicative of

those sentiments was that, according to the NTO, more than half of organ-donation-eligible patients' relatives refused to consent to the organs' removal (kathimerini.gr, 2018). Interestingly, as reported by a researcher's clinical experience, many patients often discussed the possibilities of organ trafficking or bribery in the organ transplant system (amna.gr, 2021).

It is indeed obvious that a wide-spread, well-organized campaign for raising awareness could very well lead to saving lives. The "Unlimited Breath" Campaign managed to do just that by familiarizing the Greek population with the specifics of organ donation. According to the campaign representative in just three months after the campaign was launched there was a threefold increase in registered organ donors nationwide. Hopefully, this is only a first step to what will eventually evolve into an even more comprehensive effort of reducing the morbidity and mortality of sick patients in Greece.

4. CONCLUSIONS

Much interesting information has been discussed in order to "uncover" Cystic Fibrosis. It is a rare and serious disease with no definitive cure. However, with the right treatment and a stable daily routine the survivability of a patient can have an increase significant enough to also increase the chances of lung transplantation. Currently, lung transplantations are one of the only ways patients can achieve a better quality of health and ensure an even longer life expectancy.

However, obscure as the transplantation process is, the general public's perception of it is hazy at best. Haphazard and insufficient information lead to people being either ignorant or unwilling to consider organ donation. Steps should be taken to reverse this situation.

That is exactly what the "Breath Unlimited" campaign set out to do. By raising awareness and promoting information about cystic fibrosis PCFA, an organization by CF patients for CF patients, and Humane managed to have a tangible effect on the public's perception of both the illness and the "solution" to it; organ donors. The success of the campaign proves the power of social advocacy in support of vulnerable or high-risk groups and proposes a way of promoting social empowerment and innovation in service of humanitarianism.

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