

RARE DISEASE CHALLENGE

RaDiChal'21

SOCIAL AWARENESS REPORT

TEAM NAME

Genes Of The Future (GOF) Team

TEAM MEMBERS

Abdurrahim TOPRAK

Beyza Gül ATEŞLİ

Enes Buğra YALÇINKAYA

TARGET DISEASE

Familial Mediterranean Fever
(FMF)

As the GOF Team, the activities we have carried out appeal to people of all ages. In particular, we aimed to show that patients with FMF are not alone and that they can make their voices heard more powerfully together with other patients. At this stage, our first step was to reach out to individuals with FMF and listen to their stories. We have turned this into an event under the title of “Rare Stories of Rare People”. In this event, individuals with FMF disease were broadcast live on Youtube and Instagram in the form of questions and answers. While organizing the Rare Stories of Rare People event, we got to know FMF patients closely, listened to their life experiences, diagnosis processes, difficulties they experienced, problems, and drug/treatment processes from FMF patients.

In order to increase public awareness in FMF disease, it was considered to listen from the eyes of both rheumatology specialists and experts in different fields. Afterwards, it was decided to organize the events to turn it into a series called "FMF Through the Eyes of a Specialist". In this series, rheumatologist Prof. Dr. With the guest of our teacher Özgür KASAPÇOPUR, the first stage was realized. A question-answer event was held on Instagram live broadcast with questions prepared by our team and questions from our audience.

Considering the effect of nutrition on FMF in our event called "FMF Through the Eyes of a Specialist", it was decided to organize an event under the name of "The Place of Nutrition in FMF". Our nutritionist Filiz KARAOĞLU agreed to answer our questions for our event. The guest of this series in June, Phd. Psychologist Özge Devezer Uslu has been with us. A question-answer event was held on Instagram live broadcast with questions prepared by our team and questions from our audience.

After preparing our hand brochures and poster designs to raise social awareness of FMF disease, brochures were handed out to raise awareness. Our posters were hung in 12 cities, and our design was published on billboards in Antalya.

Using the power of music for FMF awareness, PLAY for FMF, SAY for FMF! We wanted to be a voice for FMF patients by starting the trend. Afterwards, we released our song titled 'Rare People', which we released for awareness.

On September 17, World FMF awareness day, we managed to enter the Turkey Agenda by working on the Twitter agenda.

Our article, which we created for awareness, was published on news sites and newspapers by bringing the FMF disease to the press.

Sincan Express newspaper website link: <https://sincanekspres.com/karin-agrisi-diyip-gecmeyin-fmfin-farkinda-ol-tedavi-genlerimizde/>

Active news site: <http://www.aktifhabergazetesi.com/mobil/haber/15995/fmfin-farkinda-ol.html>

Turkey Havadis website: <https://www.turkiyehavadis.com/fmf-farkindaligina-ogrenci-duyarliligi/54933/>

Press News Agency website: <http://www.basinhaberajansi.com/haber/10053/karin-agrisi-diyip-gecmeyan-fmfin-farkinda-ol.html>

Başkent Post website: <https://baskentpostasi.com/haber/fmfin-farkinda-ol-h9269.html>

Expected Havadis website: <http://www.beklenenhavadis.com/karin-agrisi-diyip-gecmeyan-fmfin-farkinda-ol-1415h.htm>

Central Anatolian Union website:

<http://www.icanadolubirligi.com/?Syf=26&Syz=741897&>

Edirne Media Tv website: <https://www.edirnemedya.net/saglik/karin-agrisi-deyip-gecme-h4177.html>

Our poster has been published on Hayatdan.net.

Hayatdan.net site: [GOF TEAM AFİŞ - Hayattan.Net](#)

Our interview with Mr. Ömer, one of the team members of Hayattan.net, has been published.

Interview link: <http://hayattan.net/turkiyenin-devrimi/>

GOF TEAM Instagram Account Name: gofteam.fmf

GOF TEAM Instagram Account Link:

https://instagram.com/gofteam.fmf?utm_medium=copy_link

GOF TEAM Twitter Account Name: gofteam_fmf

GOF TEAM Twitter Account Link: https://twitter.com/gofteam_fmf?s=21

GOF TEAM Facebook Account Name: gofteam.fmf

GOF TEAM Facebook Account Link: <https://www.facebook.com/gofteam.fmf>

GOF TEAM YouTube Account Name: Genes Of The Future

GOF TEAM YouTube Account Link:

https://youtube.com/channel/UC6MNf5rpIu75c_3ztYqhzrg

GOF TEAM Website Link: <https://genesofthefuturete.wixsite.com/website>

GOF TEAM Discord Account Name: Genes of The Future “GOF TEAM”

GOF TEAM Discord Account Link: <https://discord.gg/ThguUDme>



KARIN AĞRISI DİYEREK GEÇMEYİN! FMF'İN FARKINDA OL!

FMF; NADİR GÖRÜLEN KALITSAL BİR HASTALIKTIR.



Burayı Okut!

#FMFiÇİNÇAL
#FMFiÇİNSÖYLE

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gofteam.fmf



gofteam_fmf



Genes of the Future

Figure 1. Poster Design



KARIN AĞRISI DİYEREK GEÇME!

#FMFİNFARKINDAOL! #TEDAVİGENLERİMİZDE!

FMF; NADİR GÖRÜLEN KALITSAL BİR HASTALIKTIR.

BİRLİKTE
FARKINDAYIZ!

BİRLİKTE DAHA
GÜÇLÜYÜZ!

BİRLİKTEYKEN
ATAKLAR
ENGEL
DEĞİL!

#FMFİNFARKINDAOL #FMFİÇİNÇAL #FMFİÇİNSÖYLE #FMF
#NADİRHASTALIKLAR #GOFTEAM #AİLEVİAKDENİZATEŞİ



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goftteam.fmf



goftteam_fmf



Genes of the Future

Figure 2. Poster Design



Figure 3. Brochure Design – Front and Back



Figure 4. Bookmark Design 1- front side



Figure 6. Bookmark Design 2- front side



Figure 8. Bookmark Design 3- front side



Figure 5. Bookmark Design 1- back side

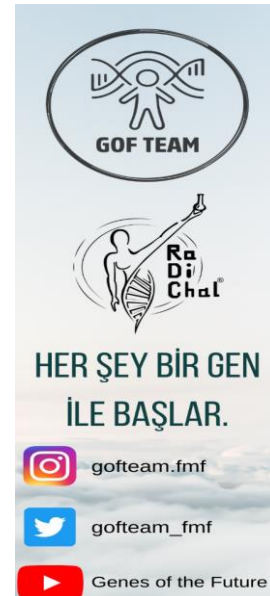
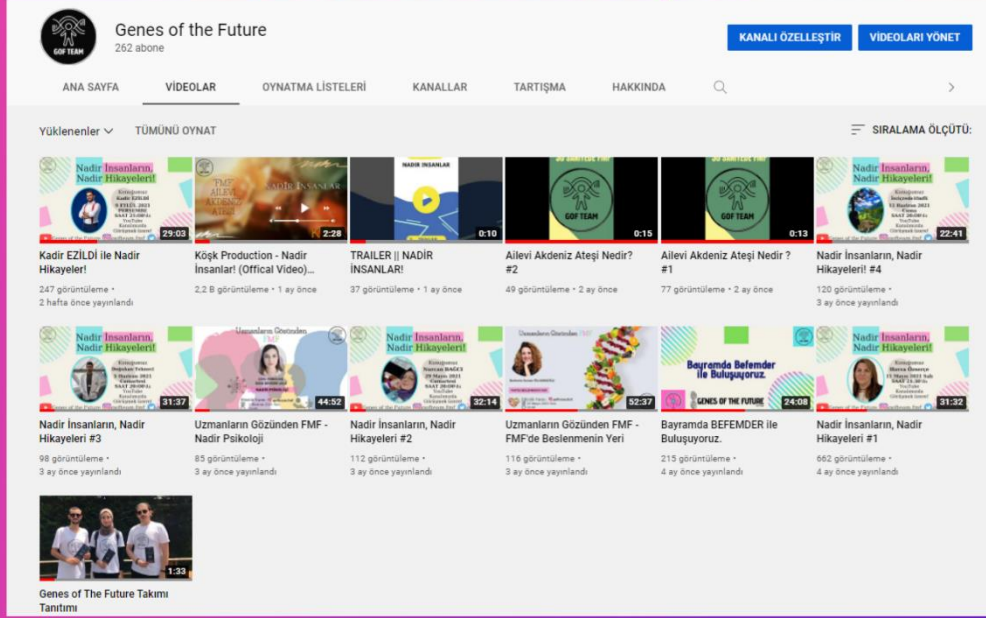


Figure 7. Bookmark Design 2- back side

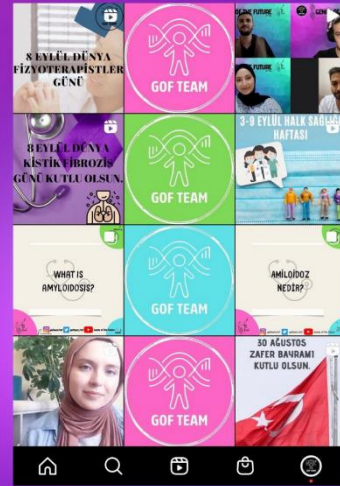
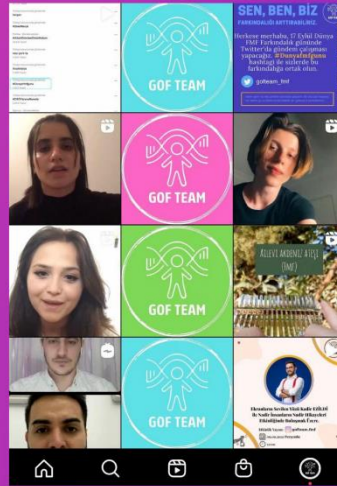


Figure 9. Bookmark Design 3- back side

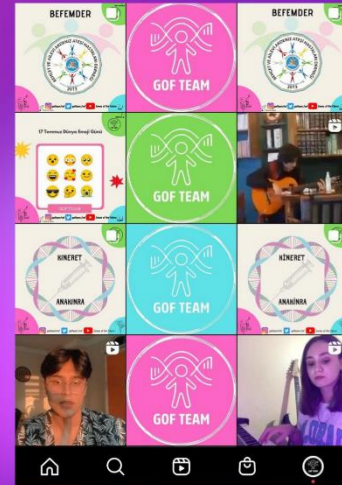
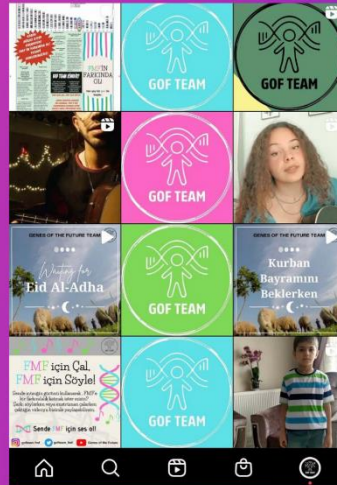
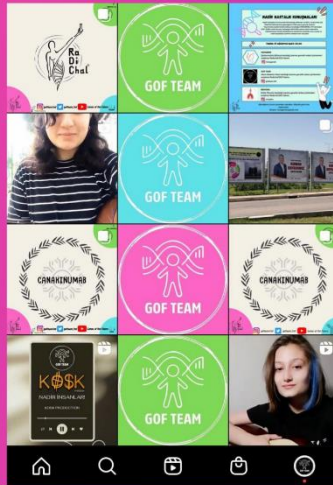
YouTube Account Layout



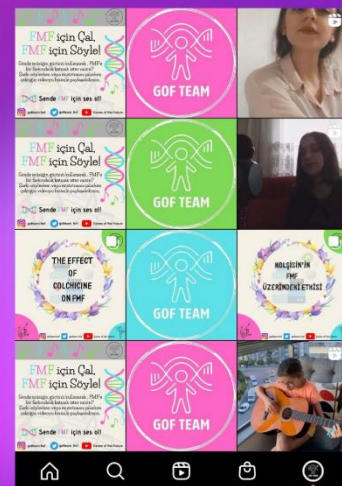
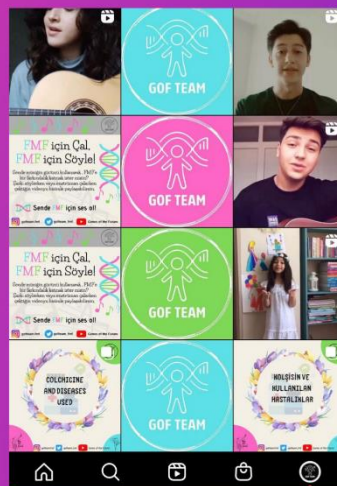
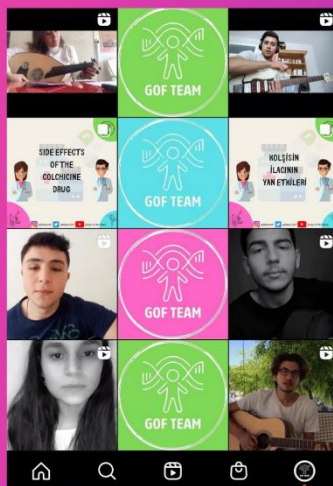
INSTAGRAM ACCOUNT PROFILE LAYOUT



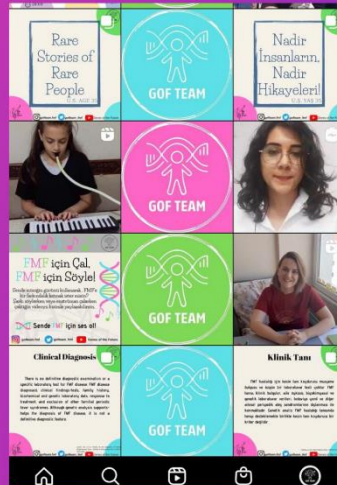
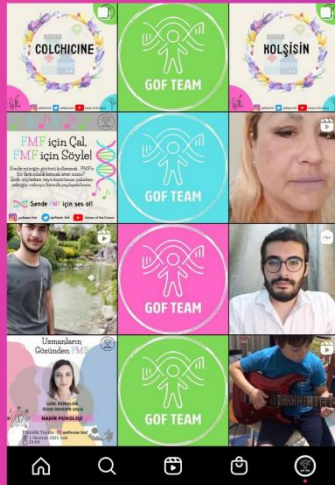
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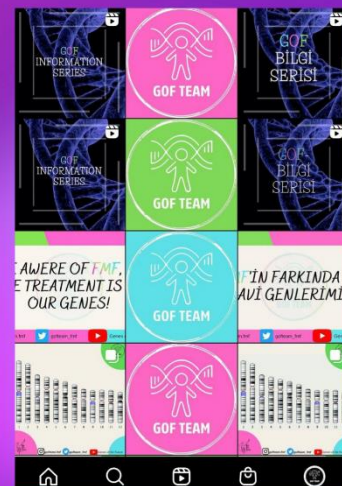
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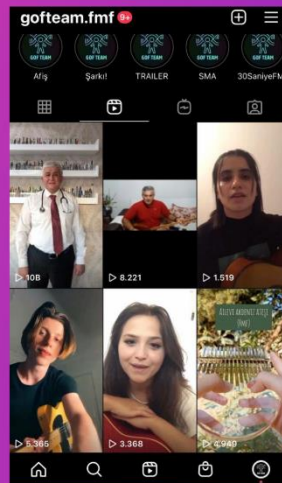
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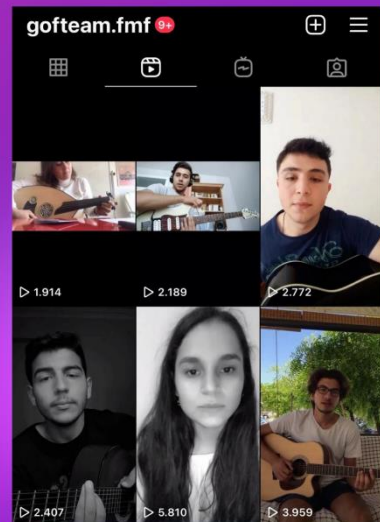
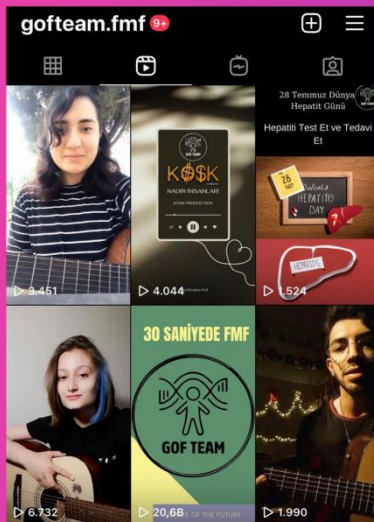
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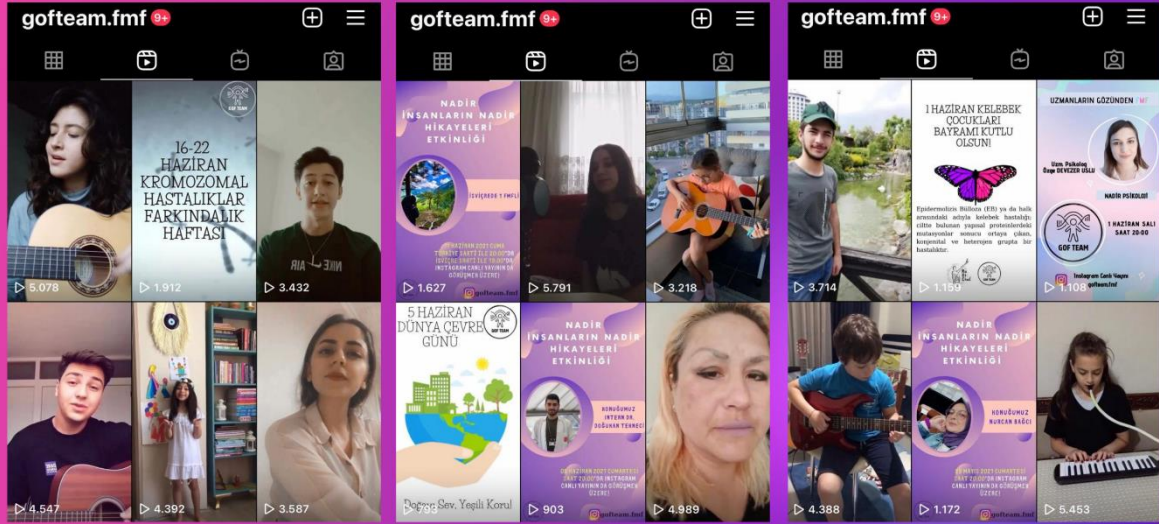
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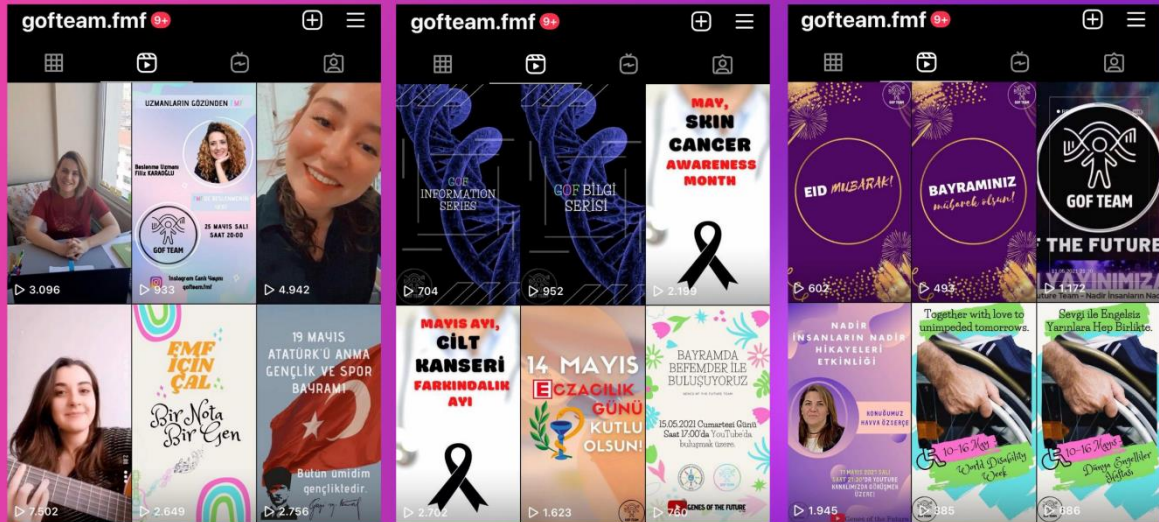
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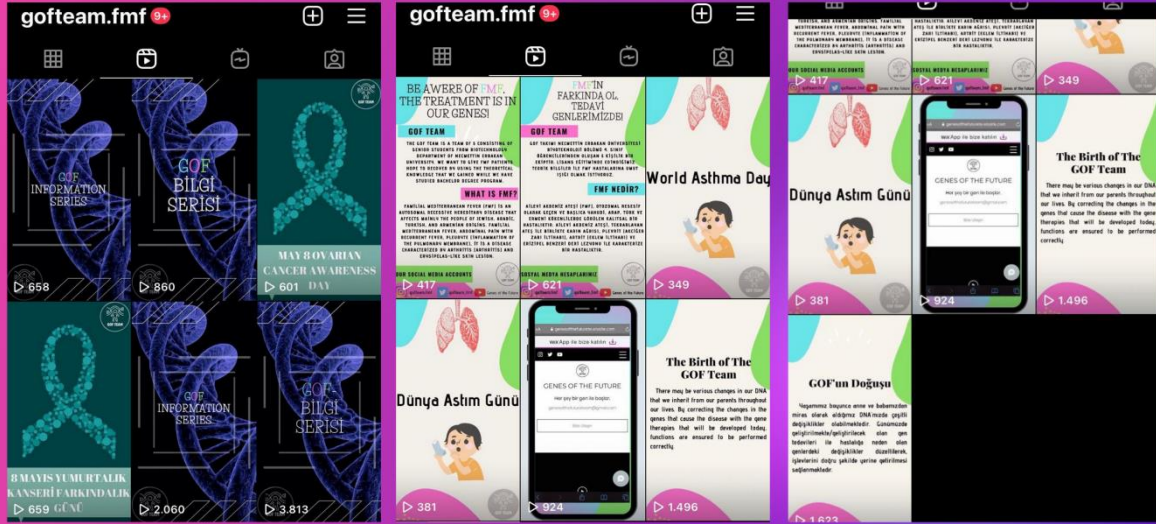
INSTAGRAM ACCOUNT PROFILE LAYOUT - REELS



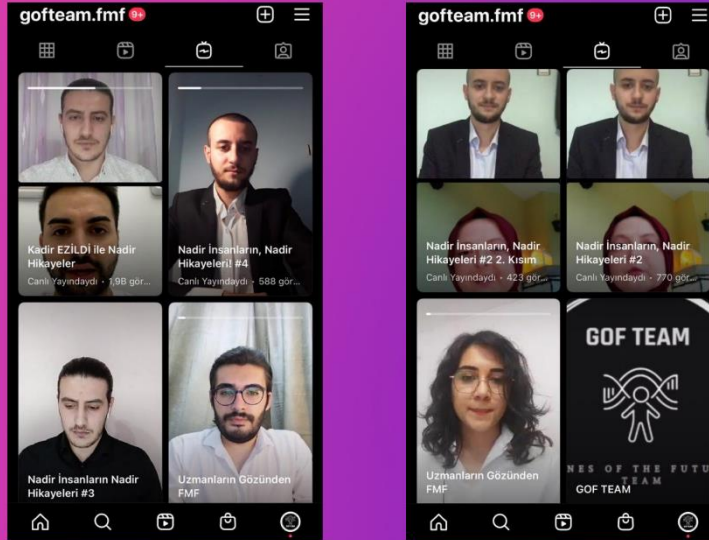
INSTAGRAM ACCOUNT PROFILE LAYOUT - REELS



INSTAGRAM ACCOUNT PROFILE LAYOUT - REELS



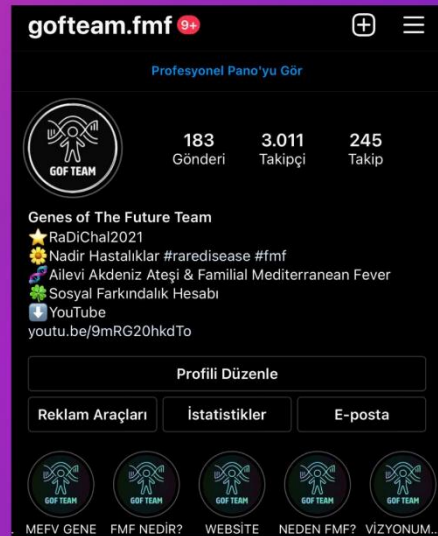
INSTAGRAM ACCOUNT PROFILE LAYOUT - IGTV



INSTAGRAM ACCOUNT PROFILE LAYOUT - HIGHLIGHTS



INSTAGRAM ACCOUNT PROFILE LAYOUT - HIGHLIGHTS



Event: Rare Stories of Rare People program

Aim: We aimed to show that patients with FMF are not alone and that they can make their voices heard more powerfully together with other patients.

Result: By organizing a live broadcast event with 5 different guests, a total of 61,534 people watched our broadcasts.

Event: FMF Through the Eyes of Experts

Aim: To listen from the eyes of both rheumatology specialists and experts in different fields in order to increase public awareness in FMF disease.

Result: By organizing a live broadcast event with 3 different guests, a total of 3,556 people watched our broadcasts.

Event: FMF in the Press

Aim: To raise awareness of readers about 'rare diseases and FMF' on news sites.

Result: Our article that we prepared for awareness was published in 8 news sites and newspapers in total.

Event: Aware Cities – Billboard Study with GOF Team

Aim: To inform people by hanging the billboard design that we have prepared on the billboards in the densely populated areas of the cities. While preparing the design of our poster, we included the symptoms of our disease. We aimed to give the message that we are stronger together by putting a picture of people hugging each other.

Target: To appear at bus stops and on billboards.

Result: Our 2 Turkish and 1 English designs in Antalya-Muratpaşa region were hung in 3 busy areas of the city. At the Ankara-Sincan Municipality council meeting, a proposal was presented under the name of "FMF Disease Social Awareness Study" and it was approved by the parliament. A meeting was held with Edirne Municipality through the owner of Edirne TV Media and it was concluded positively. There is a queue for Edirne billboards. We have met with Karaman Municipality and received a positive response from there. Finally, we continue to meet with Samsun Municipality.

Event: Awareness Song Project – Rare People!

Aim: To raise awareness by using the power of music.

Target: Publishing the awareness song on social media.

Result: The awareness song was shared with an informative clip video on the YouTube platform. We got 2,276 views.

Event: STEAL for FMF, TELL for FMF!

Aim: To start a trend with music on social media.

Target: Play and sing for FMF from seventy to seventy and show that we stand by FMF patients.

Result: About 50 people played for FMF and sang for FMF by joining this trend.

Event: Poster Work

Aim: To raise awareness by hanging posters in different cities. We used 2 designs while preparing our poster. We included the symptoms of the disease in our first poster design. In our second poster, we aimed to convey the message that we are stronger together and we are aware through the picture of people hugging each other.

Target: We aimed to hang our posters in streets and neighborhoods with at least 2 posters in every city.

Result: Our posters were hung at more than 50 points in 12 cities.

Event: Brochure Work

Aim: To raise awareness by distributing brochures in different cities. In our brochure content; What is a rare disease, familial mediterranean fever (FMF) disease, symptoms, clinical diagnosis, RaDiChal competition, BEFEMDER, PLAY for FMF, TELL for FMF! We included the event and our social media accounts.

Target: We aimed to distribute 100 brochures.

Result: Our brochures were distributed in 8 cities in total.

Event: Twitter agenda work

Aim: To raise awareness of FMF disease by working on the twitter agenda on September 17, World FMF Day.

Target: To enter the agenda of Turkey.

Result: We entered the agenda of Turkey with 1532 tweets.

Events we held in May



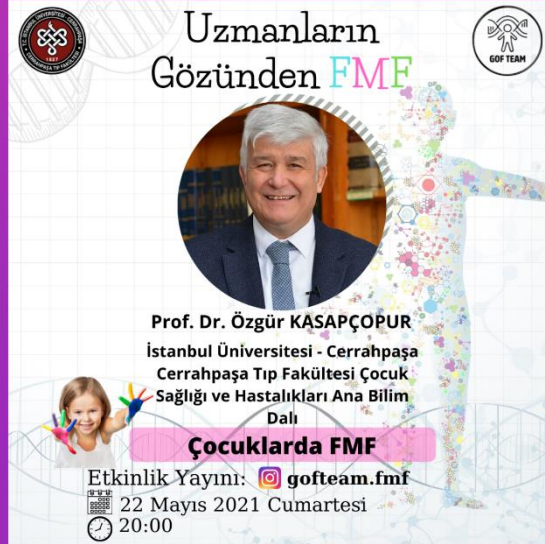
RARE STORIES OF RARE PEOPLE EVENT WAS HELD ON YOUTUBE AND INSTAGRAM LIVE BROADCAST WITH FMF PATIENT MS. HAVVA AND MS. NURCAN.

FMF ACTIVITY THROUGH EXPERTS PROF. DR. IT WAS HELD ON INSTAGRAM LIVE BROADCAST WITH OUR TEACHER ÖZGÜR KASAPÇOPUR AND NUTRITION SPECIALIST FİLİZ KARAOĞLU.

FMF THROUGH THE EYES OF SPECIALISTS

In order to increase public awareness in FMF disease, it was considered to listen from the eyes of both rheumatology specialists and experts in different fields. Afterwards, it was decided to organize the events to turn it into a series called "FMF THROUGH THE EYES OF SPECIALISTS". In this series, rheumatologist Prof. Dr. With the guest of our teacher Özgür KASAPÇOPUR, the first stage was realized. A question-answer event was held on Instagram live broadcast with questions prepared by our team and questions from our audience.

Event stats:
Number of Live Views: 1000+



FMF THROUGH THE EYES OF SPECIALISTS

Considering the effect of nutrition on FMF in our event called "FMF THROUGH THE EYES OF SPECIALISTS", it was decided to organize an event under the name of "The Place of Nutrition in FMF". Our nutritionist Filiz KARAOĞLU agreed to answer our questions for our event. Our event also mentioned that although eating any vegetables and fruits in FMF patients does not cause health problems, individuals using drugs should not consume grapefruit.

Event stats:

Number of Live Views: 219

IGTV views: 1171

YouTube views: 116



"RARE STORIES OF RARE PEOPLE!" EVENT

As the GOF team, the activities we have carried out appeal to people of all ages. In particular, we aimed to show that patients with FMF are not alone and that they can make their voices heard more powerfully together with other patients. At this stage, our first step was to reach out to individuals with FMF and listen to their stories. We have turned this into an event under the title of "Rare Stories of Rare People". In this event, individuals with FMF disease were conveyed to us in the form of questions and answers, both by broadcasting live on Youtube and Instagram, and by sending our questions to the sick individuals.

Event stats:

Number of Live Views: 170

YouTube views: 661



"RARE STORIES OF RARE PEOPLE!" EVENT

While organizing the Rare Stories of Rare People event, we got to know FMF patients closely, listened to their life experiences, diagnosis processes, difficulties they experienced, problems, and drug/treatment processes from FMF patients.

Event stats:

Number of Live Views :352

IGTV views: 1193

YouTube views: 112



"WE ARE MEETING WITH BEFEMDER ON HOLIDAY!" EVENT

We realized our meetings with the BEFEMDER Association, introduced our group to the association on Saturday, 15.05.2021 at 17:00, and learned the mission and visions of the association, and understood their activities. In this live broadcast, information about the convenience and difficulties encountered in the establishment of the association and how to become a member of the association were obtained.

Event stats:

Number of live views : 71

Current view count : 215



MAY STEAL FOR FMF TELL FOR FMF



CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN MAY

OUR MISSION

Familial Mediterranean Fever, one of the rare genetic diseases, is one of the rare diseases seen primarily in our country and in the world. Our biggest goal is to create a genetic treatment method against this disease.

[@gofteam.tr](#) [gofteam_tr](#) [Genes of the Future](#)

OUR VISION

To understand the problems of individuals with familial Mediterranean fever, to find the right treatment method for them and to be with them in this difficult process.

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The Birth of The GOF Team!

There may be various changes in our DNA that we inherit from our parents throughout our lives. By correcting the changes in the genes that cause the disease with the gene therapies that will be developed today, functions are ensured to be performed correctly. As long as there is vitality, the eternal legacy of our ancestors, errors will occur in our DNA, which is the password of life, in the future as it is now, and they will need to be corrected. This is why we chose the name Genes of the Future because "We are the user and controller of our genes, the author of our biological story".

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Why FMF?

It is a rare disease called Familial Mediterranean Fever (FMF), which is seen in many countries around the world. Although it is known as a rare disease, to increase the quality of life of individuals with FMF disease, which is frequently seen in our country and in the world, we chose FMF disease to stand next to them and be a voice for them.

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What is Familial Mediterranean Fever?

Familial Mediterranean Fever (FMF) is an autosomal recessive hereditary disease that affects mainly the people of Jewish, Arabic, Turkish, and Armenian origins. Familial Mediterranean Fever, abdominal pain with recurrent fever, pleurisy, it is a disease characterized by arthritis and erysipelas-like skin lesion. The diagnosis of Familial Mediterranean Fever is based mainly on clinical findings, therefore, many patients with Familial Mediterranean Fever experience diagnostic difficulties. Familial Mediterranean Fever is an autoinflammatory disease caused by homozygous or heterozygous mutations in the MEV gene encoding pyrin (marennosin protein). The MEV gene is in the 16p13.3 region of the 16th chromosome.

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Primary Constitution - Cytoskeleton
Secondary Constitution
p - Short Arm
q - Long Arm

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BE AWARE OF FMF, THE TREATMENT IS IN OUR GENES!

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CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN MAY

FMF's WIDESPREAD SYMPTOMS

High Fever

Although there may be rare attacks with only high fever, they are mostly seen together with other clinical symptoms. Fever stays high during the attack. Almost all patients have a fever at some stage of their seizures. But there are low numbered patients who had a feverless seizure. The fever range can be mild to up to 40°C. Fever can stay high for a few hours to four days but usually subsides within 24 hours. In some patients, the fever may not be very high and therefore may be overlooked. Also within the same patient, some seizures have a high fever and the others can have a mild fever. Systemic fever may not be observed in joint attacks. Fever may not be seen in the seizures of patients receiving colchicine treatment.

Abdominal Attacks

The most common feature in 95% of patients with FMF is abdominal pain. Abdominal pain can be severe enough to require bed rest, diffuse or localized enough to mimic peritonitis (inflammation of the peritoneum). The pain usually begins a few hours before the fever and continues for another 1-2 days after the fever subsides. Some patients may have acute abdomen pain, which causes many patients to go under appendectomy (appendicitis surgery) and laparotomy (surgical opening of the abdominal cavity) procedures unnecessarily.

Joint Attacks

It is the third most common (30%) clinical symptom which is seen in patients after fever and abdominal pain. It also can occur without fever and/or abdominal pain. Joint involvement is seen as arthritis (joint inflammation) in 30% of cases and as arthralgia (joint pain) in 30% of cases. Classically arthritis is non-migratory, does not damage the joint, does not leave any sequela (tissue breakage due to illness), mono or oligoarticular style. Generally involves large joints and the lower limb joints. Joint attacks disappear spontaneously by themselves within a few days or 1-2 weeks.

Chest Attack

Chest pain has been reported in 50% of patients. Typical chest pain due to pleurisy (fluid buildup in the pleural) are unilateral and severe. Within physical examination due to infusion lung sounds reduction sometimes from the (the sound that occurs when the membranes surrounding the heart or lungs rub against each other as a result of inflammation) or fullness can be obtained with percussion, but there is no certain physical examination finding. Recurrent cases of pericarditis (inflammation of the pericardium) have been reported in 0-5% of patients. FMF pericarditis tends to occur in the late stages of the disease.

Dermatological Attacks

The most characteristic skin lesion in FMF is erysipelas-like erythema and it has been reported as 3-46% of the patients who seem to have these symptoms. It is most commonly seen in the lower extremity, on the anterior aspect of the leg, ankle, back of the foot or on the malleolus. They are unilateral pink-purple rashes in the form of an erythema, slightly raised from the skin, approximately 10-15 cm in diameter. The skin area where the lesion is located is tense, edematous (excess fluid buildup in tissues) and there is an increase in temperature. Symptoms usually resolve spontaneously by themselves within 2-3 days.

Scrotal Involvement

Children and young adult patients are more common so it is rare after the age of 20. It manifests itself with swelling, redness and tenderness. It resolves by itself spontaneously within 12-24 hours without leaving anatomical sequelae (tissue breakage after the illness). It usually occurs unilaterally as a result of inflammation of the tunica vaginalis in the testicle. In male patients, only scrotal swelling may be the first sign of FMF. FMF should be considered in the differential diagnosis of recurrent orchitis (testicular inflammation).

Muscle Attacks

Muscle pain may occur in 25% of the FMF patients. Muscle pain in the patient may cause a clinical presentation in the form of spontaneously healing, exercise-induced or prolonged febrile myalgia syndrome. In classical FMF myalgia, pain, sensitivity, and loss of function are less severe, unlike prolonged febrile myalgia. In prolonged febrile myalgia, joint findings are usually absent and muscle enzymes, electromyographic examinations and muscle biopsy are normal. Prolonged febrile myalgia, a rare dramatic clinical manifestation of FMF, may occur despite colchicine therapy and requires treatment with corticosteroids.

CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN MAY

Vasculitis

It is known that an important disease group associated with FMF disease is vasculitis. It should be kept in mind that vasculitis can be seen both in differential diagnosis and with FMF since the data of vasculitis and FMF attacks are similar in terms of clinical and laboratory results. The most common vasculitis in FMF is Henoch-Schönlein purpura (HSP). Another vasculitis table seen more frequently in FMF compared to the normal population is polyarteritis nodosa (PAN). FMF must be questioned in PAN emerging in childhood and youth.

Neurological Involvement

Although rare, neurological involvement may occur during FMF attacks. The most common finding in neurological involvement is a headache. Very rarely, aseptic meningitis attacks can be seen. Cases with pseudotumor cerebri and cranial nerve involvement sensitive to colchicine therapy have also been reported.

Pelvic Involvement

FMF can adversely affect fertility in female patients. The reason is thought to be pelvic adhesions secondary to inflammation or miscarriages as a result of abdominal attacks. It is known that attacks limited to the pelvic region in FMF patients stimulate the formation of pelvic inflammatory disease (PID).

Liver-Spleen Involvement

Acute hepatitis and recurrent hyperbilirubinemia (yellowing of the skin and the whites of the eyes) have been reported in FMF patients treated with colchicine. Splenomegaly is in fact seen in 30-50% of the patients. The fact that most of the rectal biopsies examined are negative for amyloid suggests that there is no amyloid accumulation as a result of splenic enlargement.

Amyloid

The most basic feature determining the prognosis of FMF disease is the presence of amyloidosis. This protein, called serum amyloid A (SAA), is produced by the liver. It is predicted to be the degradation product of an acute phase reactant generated during infection, malignancy, tissue breakage, FMF attack, and other inflammatory events. The first clinical sign of FMF-related amyloidosis is proteinuria. Proteinuria can over time cause nephrotic syndrome, uremia, and eventually kidney transplant or end-stage renal failure. Patients are generally normotensive and non-hematuric. Due to the widespread use of colchicine therapy, amyloidosis occurs in only a minority of FMF patients.

Clinical Diagnosis

There is no definitive diagnostic examination or a specific laboratory test for FMF disease. FMF disease diagnosed, clinical findings, tests, family history, biochemical and genetic laboratory data response to treatment, and exclusion of other familial periodic fever syndromes. Although genetic analysis supports, helps the diagnosis of FMF disease, it is not a definitive diagnostic feature.

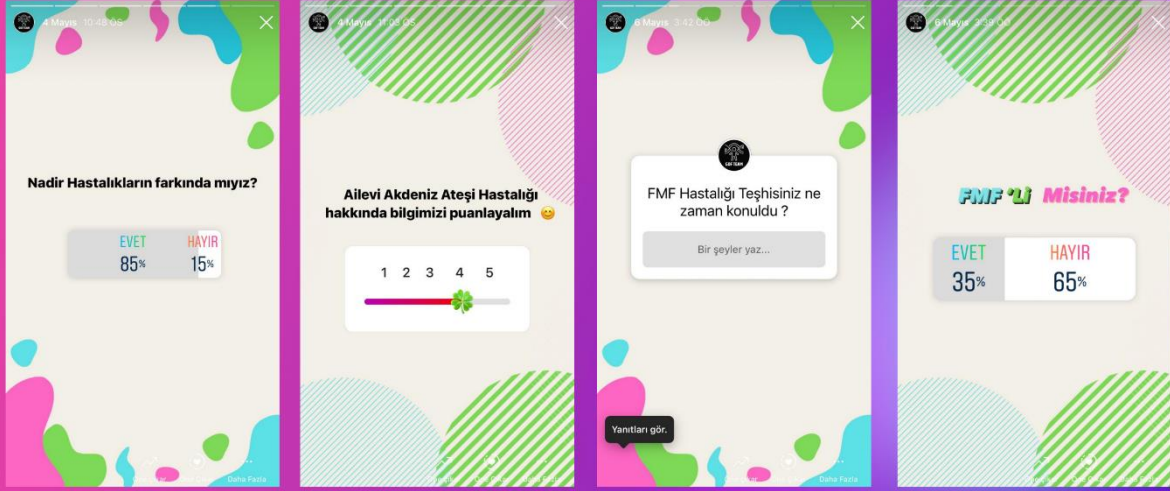
Clinical Diagnosis

If the patient is observed during the attack, the presence of inflammatory accompanying the attack (leukocytosis, sedimentation (ESR), C-reactive protein (CRP), and fibrinogen increase), and the decrease of these features in tests to normal values after the attack ends, helps the diagnosis of the FMF. It should be kept in mind that the positive results of these tests are not specific to the FMF, but only shows the presence of inflammation in the body. Some accepted diagnostic features are used in clinical practice to diagnose the disease.

Rare Stories of Rare People

U.S. AGE 35

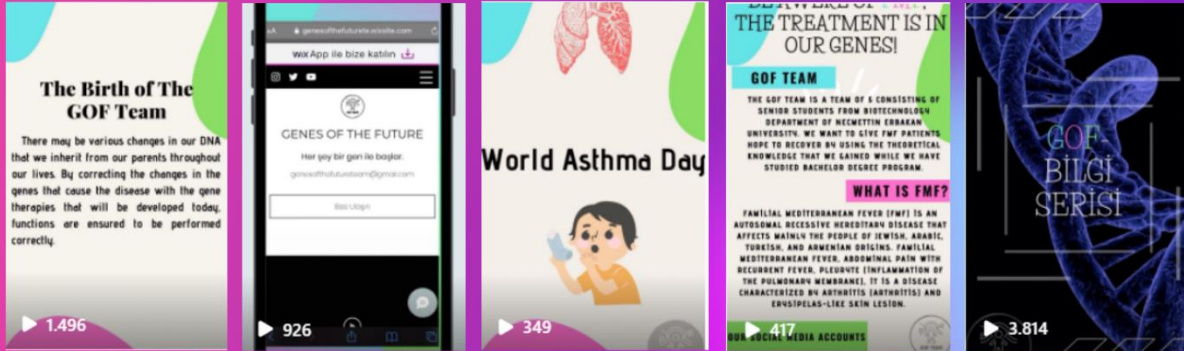
INSTAGRAM STORIES WE SHARED IN MAY



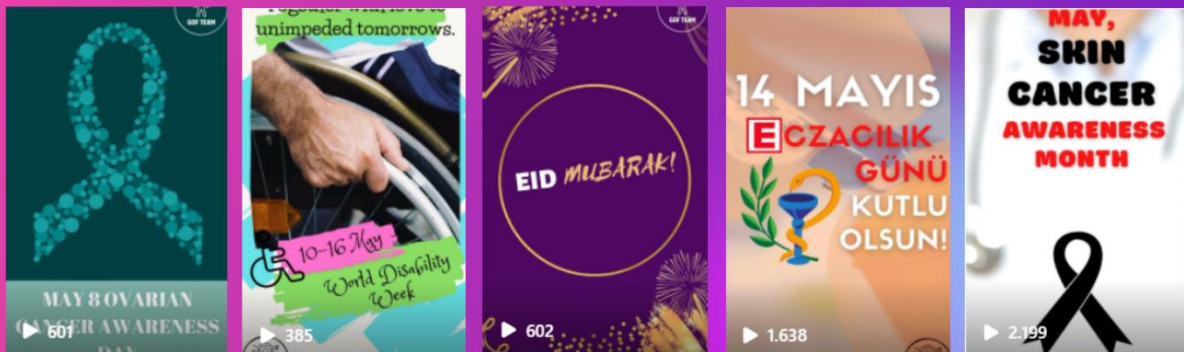
INSTAGRAM STORIES WE SHARED IN MAY



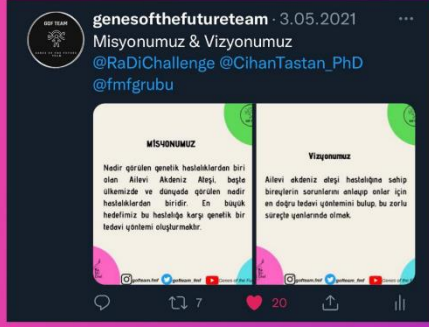
REELS VIDEOS WE SHARED IN MAY



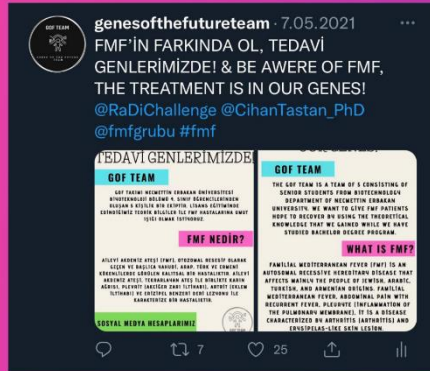
REELS VIDEOS WE SHARED IN MAY



SHARE ON TWITTER IN MAY



SHARE ON TWITTER IN MAY



SHARE ON TWITTER IN MAY



ACTIVITIES WE CARRIED OUT IN JUNE



THE RARE STORIES OF RARE PEOPLE EVENT WAS HELD ON INSTAGRAM LIVE WITH FMF PATIENT DOÇUKAN AND MS. ÜMMÜHAN.

OUR EXPERT PSYCHOLOGIST ÖZGE DEVEZER USLU AND THE FMF EVENT FROM THE EXPERTS WAS HELD ON INSTAGRAM LIVE BROADCAST.

FMF THROUGH THE EYES OF SPECIALISTS

It was decided to organize the events to turn it into a series called "FMF THROUGH THE EYES OF SPECIALISTS". The guest of this series in June, Expert Psychologist Özge Devezer Uslu was with us. A question-answer event was held on Instagram live broadcast with questions prepared by our team and questions from our audience.

Event stats:

Number of Live Views: 201

IGTV views: 765

YouTube views: 84



"RARE STORIES OF RARE PEOPLE!" EVENT

It is one of the major problems that FMF patients are diagnosed late in general and that they are confused with various diseases during this diagnosis process. This has caused many people to have appendicitis because of misdiagnosed. Many patients have intestinal problems. In this diagnostic process, it was realized that family histories are important. It is also noteworthy that FMF disease is transmitted from generation to generation due to consanguineous marriage.

Event stats:

Number of Live Views : 153

IGTV views: 475

YouTube views: 98



"RARE STORIES OF RARE PEOPLE!" EVENT

One of the other problems experienced by FMF patients is that the frequency and severity of attacks increase when colchicine is not used, and such patients remain dependent on colchicine for life. In patients resistant to colchicine, they use interleukin-1 inhibitor drugs. It was learned that the interviewed patients had diarrhea due to the use of colchicine. Due to this side effect, it has been realized that patients try to balance this situation by taking supplements. We learned that patients do not use colchicine on special days, so that it does not affect their social lives. Although it is rare, a patient we contacted had to have a kidney transplant due to amyloidosis and protein leakage, and it was stated that the transplanted kidney had amyloidosis again. The use of immunosuppressives due to kidney transplantation also makes the current pandemic vulnerable. In addition, this patient is receiving cancer and chemotherapy.

Event stats:

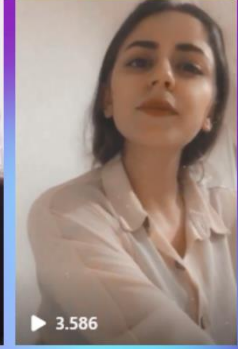
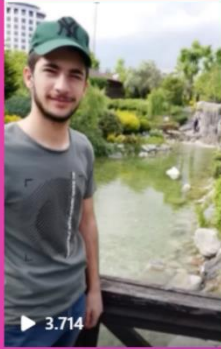
Number of Live Views :138

IGTV views: 588

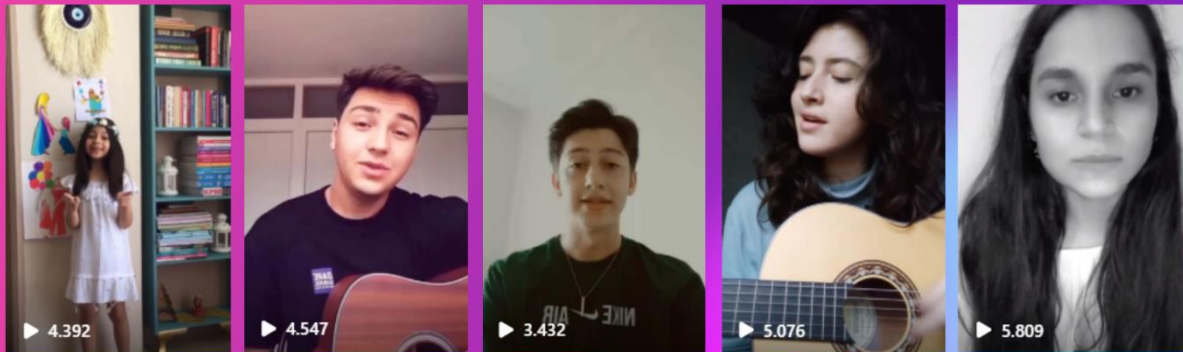
YouTube views: 120



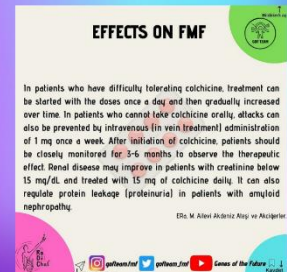
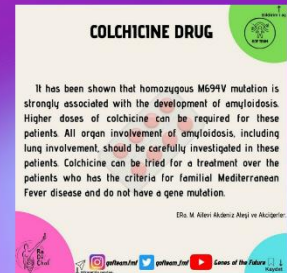
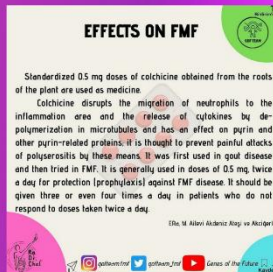
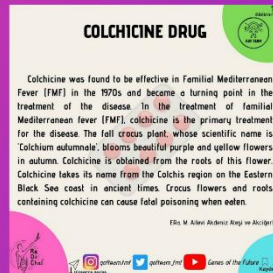
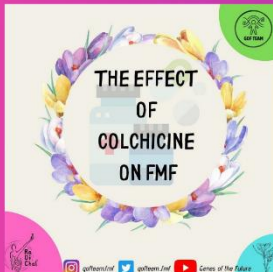
JUNE STEAL FOR FMF TELL FOR FMF



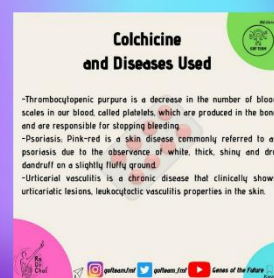
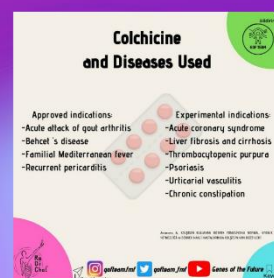
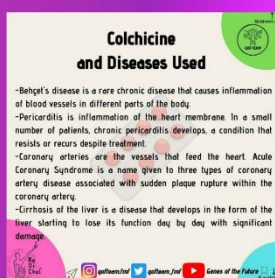
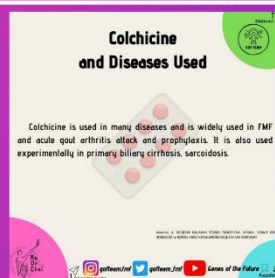
JUNE STEAL FOR FMF TELL FOR FMF



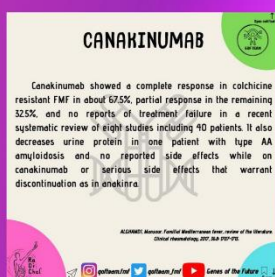
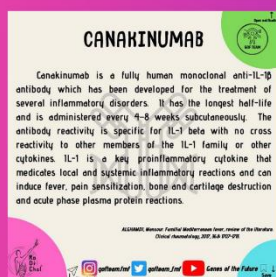
CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JUNE



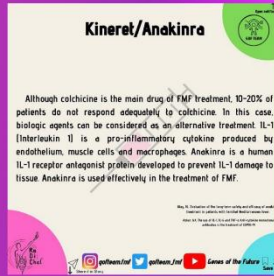
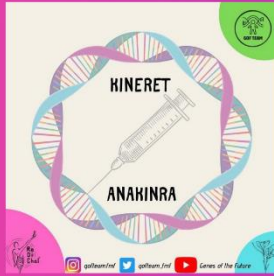
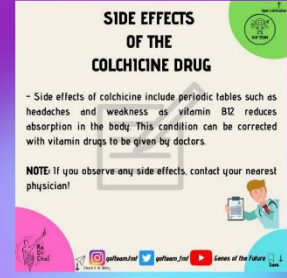
CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JUNE



CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JULY



CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JULY



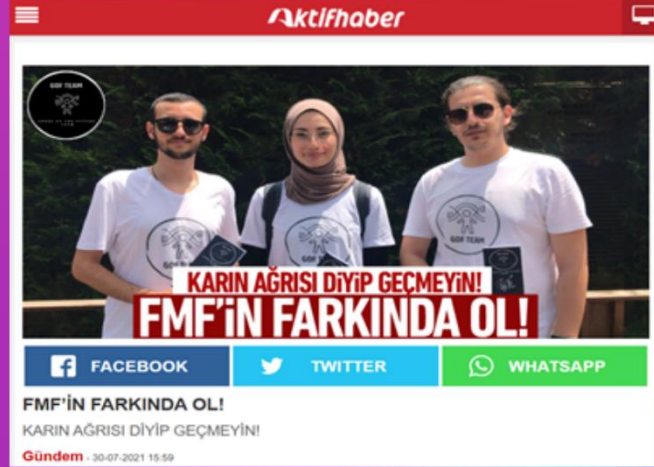
INSTAGRAM STORIES WE SHARED IN JULY



ACTIVITIES WE TAKE IN JULY



sincanekspres for familial Mediterranean fever -FMF- awareness newspaper 13 July 2021
They gave us a place in the 20th issue of the date.



Active News for Familial Mediterranean Fever -FMF- awareness website 30 July 2021
They also gave us a place in history.

ACTIVITIES WE TAKE IN JULY



On July 31, 2021, our article was published on Turkey Havadis website to create social awareness.



Our article was published on the Press News Agency website on 31 July 2021 to create social awareness.

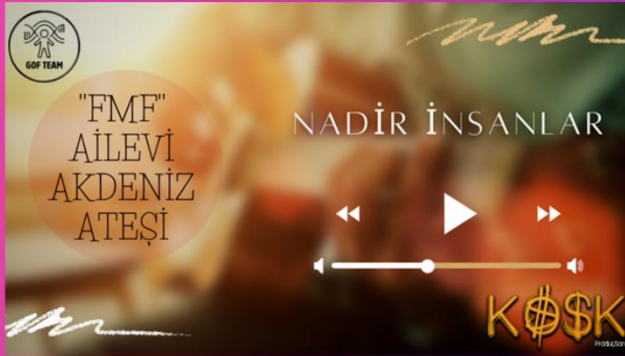
ACTIVITIES WE TAKE IN JULY



In the meetings held with Antalya Muratpaşa Municipality in July, they said that they would take us on billboards and on 16 July 2021 they hung our billboard designs that we prepared in both English and Turkish.



ACTIVITIES WE TAKE IN JULY



We have published our awareness song project on our Genes Of The Future Youtube channel on July 29, 2021 at 20:00, as we think that the concept of familial Mediterranean Fever (FMF) disease and rare diseases will have a good effect on people by using the power of music.



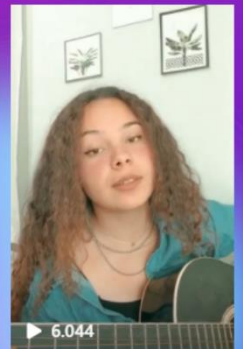
We prepared a video called FMF in 30 seconds and shared our video by briefly explaining FMF in 30 seconds.

Link to our 'Rare People' awareness song: <https://youtu.be/9mRG20hkdTo>

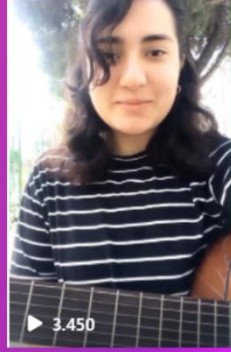
JULY STEAL FOR FMF TELL FOR FMF



JULY STEAL FOR FMF TELL FOR FMF



JULY STEAL FOR FMF TELL FOR FMF



JULY - BROCHURE DISTRIBUTION



ANKARA

-

İSTANBUL

CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN AUGUST



REELS VIDEOS WE SHARED IN JUNE-JULY-AUGUST



ACTIVITIES WE TAKE IN AUGUST



On August 2, 2021, our article was published on the Başkent Postası website to create social awareness.

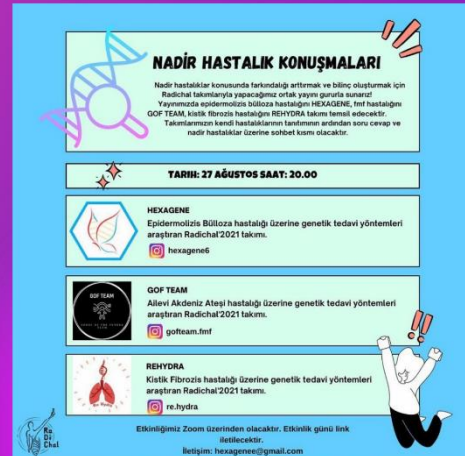


On August 3, 2021, our article was published on the Central Anatolian Union website to create social awareness.

ACTIVITIES WE TAKE IN AUGUST



Our article was published on the Expected Havadis website on August 3, 2021 to create social awareness.



The 'Rare Disease Talks' event was hosted by the hexagene6 team. In the event we held together with the hexagene6 and re.hydra teams, first of all, the diseases of the teams were introduced, and then we had a question-answer and conversation about rare diseases.

AUGUST - BROCHURE DISTRIBUTION



KONYA

AUGUST - POSTER WORK



NIGDE - SAHIN ALI NEIGHBORHOOD



NIGDE - EMIN ERISINGIL AVENUE

AUGUST - POSTER WORK



ERZİNCAN - OFFICE BLOCK - 13 FEBRUARY AVENUE- MANİFATURACILAR SITE - DÖRTYOL

AUGUST - POSTER WORK



BURSA - KULTURPARK - ALTINPARMAK NEIGHBORHOOD- SELİMİYE NEIGHBORHOOD

CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN SEPTEMBER



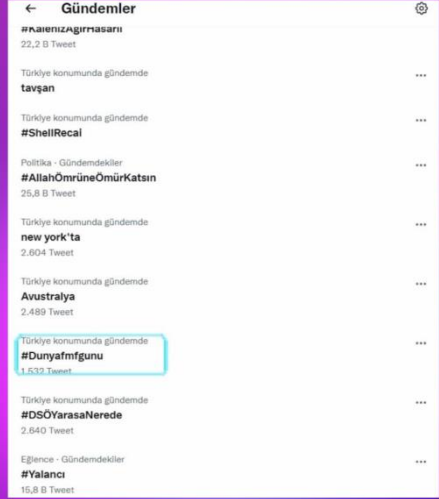
SEN, BEN, BİZ FARKINDALIĞI ARTTIRABİLİRİZ.

Herkese merhaba, 17 Eylül Dünya FMF Farkındalık gününde Twitter'da gündem çalışması yapacağız. **#Dunyafmfgunu** hashtagi ile sizlerde bu farkındalığa ortak olun.

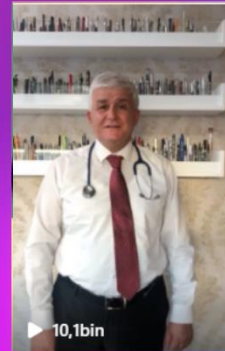
goftteam_fmf

Adım adım ve hep birlikte harekete geçelim. Bir olursak hepimiz için daha iyi ve daha sürdürülebilir bir gelecek inşa edebiliriz.

17 EYLÜL DÜNYA FMF FARKINDALIK GÜNÜ



REELS VIDEOS WE SHARED IN SEPTEMBER



ACTIVITIES WE TAKE IN SEPTEMBER

SEN, BEN, BİZ

FARKINDALIĞI ARTTIRABİLİRİZ.



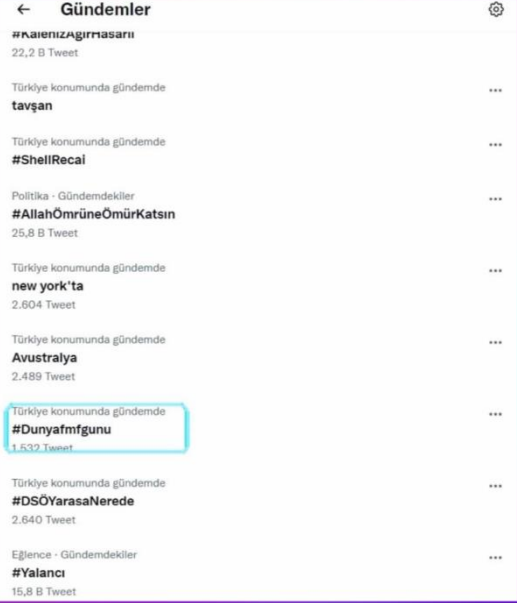
17 EYLÜL DÜNYA FMF FARKINDALIK GÜNÜ

Herkese merhaba, 17 Eylül Dünya FMF Farkındalık gününde Twitter'da gündem çalışması yapacağız. **#Dunyafmfgunu** hashtagi ile sizlerde bu farkındalığa ortak olun.

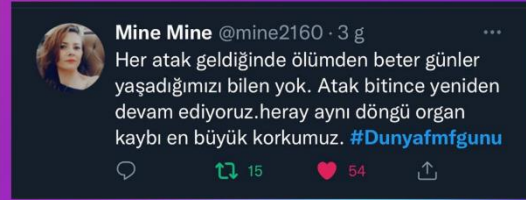


Adım adım ve hep birlikte harekete geçelim. Bir olursak hepimiz için daha iyi ve daha sürdürülebilir bir gelecek inşa edebiliriz.

Twitter agenda work was carried out on 17 September World Familial Mediterranean Fever Awareness Day. With the hashtag #Dunyafmfgunu, we managed to enter the agenda in Turkey.



17 SEPTEMBER WORLD FMF DAY TWITTER AGENDA WORK



Fruktozemi-Fruktosemia @fruktu... - 4 g ...
Büyük FMF'nin farkındayız.Ya siz? #Dunyafmfgnu

@fmfgrubu

7 12

Eda Lököglü @edalokglu - 3 g ...
#Dunyafmfgnu farkında ol !

2 8

Beyza Gül Ateşli @beyzaguls - 3 g ...
#Dunyafmfgnu hashtag i sizde bizlere destek olun. Nadir hastalıkların farkında olalım.

@saaglikbakanligi @drfahrettinkoca

Beyza Gül Ateşli @beyzaguls - 3 g ...
#17EylülFMFGünü benim için ilk defa farklı geçiyor. @RaDiChallenge yarışmasına katıldıktan sadece 1 ay sonra FMF teşhisi konuldu ve yaklaşık üç aydır FMF hastası olduğumun farkındayım. Bu gün bizim günümüz! #Dunyafmfgnu #CihanTastan_PHD @NesrinOzoren

9 22

narinhilali @narinbirli - 3 g ...
Farkındalık ve erken tanı #Dunyafmfgnu

2 9

narinhilali @narinbirli - 3 g ...
Evlilik öncesi gen testi yapılmalı #Dunyafmfgnu

5 13

narinhilali @narinbirli - 3 g ...
Nadir hastalıkların farkında olalım #Dunyafmfgnu

4 6

güllühamaloğlu @gulluhamlo - 3 g ...
20 senedir konulan teşhis, kalitele bir yaşam ve yok sayılan bir hastalık. Biz vnz ve maalesef çok fazlayız #Dunyafmfgnu

1 4 16

narinhilali @narinbirli - 3 g ...
Kimse bu hastalık yüzünden benim yaşadıklarımı yaşamamı, farkındalık artırsın #Dunyafmfgnu

7 13

narinhilali @narinbirli - 3 g ...
Farkında olalım ki farkındalık artırsın #Dunyafmfgnu

6 13

myay @myaymyayay - 3 g ...
17 Eylül Dünya FMF Farkındalık Günü'nün FMF(Akdeniz Ateşi) atağının tuttuğu gününe denk gemesi de benim için ayrıca manidar oldu. Allah'ın eli zor asla düşmez. (bu tithi saçmalar içinde atlatılır) #Dunyafmfgnu

Ayşe Erdem @AyseErdem46963401 - 3 g ...
#Dunyafmfgnu Doktorlar ve sağlık bakanlığı da farkında olmalı!

17 Eylül Dünya Ailevi Akdeniz Ateşi (FMF) ve Otoenflamatuvar Hastalıkların Farkındalık Günü

Ailevi Akdeniz Ateşi (Familial Mediterranean Fever, FMF), kronik, ağrıya ve eklem ağrısına eşlik eden otoenflamatuvar bir genetik hastalıktır. Karakteristik bir hastalıktır. Genetik tanımlanmış hastalıklardır. Akdeniz kökenli gruplarda daha çok görülmesine birlikte her ailede sadece kardeşler hastalıklıdır.

NADİRİN FARKINDAYIZ !

SEN, BEN, BİZ
FARKINDALIĞI ARTTIRABİLİRİZ.

Herkese merhaba. 17 Eylül Dünya FMF Farkındalık gününde Twitter'da gündem çalışması yapacağız. #Dunyafmfgnu hashtagi ile sizlerde bu farkındalığı ortak olun.

gocemam_fm

SEN, BEN, BİZ
FARKINDALIĞI ARTTIRABİLİRİZ.

Herkese merhaba. 17 Eylül Dünya FMF Farkındalık gününde Twitter'da gündem çalışması yapacağız. #Dunyafmfgnu hashtagi ile sizlerde bu farkındalığı ortak olun.

gocemam_fm





TÜRKİYE'NİN DEVRİMİ
19 EYLÜL PAZARI
Hayatın Engelsiz Tarafı
www.hayattan.net'te
Benim Hikayem Bölümünde



Ekranların Sevilen Yüzü Kadir EZİLDİ
ile Nadir İnsanların Nadir Hikayeleri
Etkinliğinde Buluşmak Üzere.

Hayatın Engelsiz Tarafı
www.hayattan.net



Etkinlik Yayını:  **gofteam.fmf**

 **09.09.2021 Perşembe**

 **21:00**

Hayatın Engelsiz Tarafı
www.hayattan.net



Our interview and poster design on Hayatdan.net has been published.

"RARE STORIES OF RARE PEOPLE!" EVENT

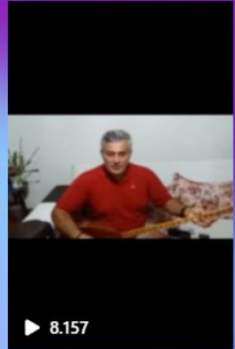
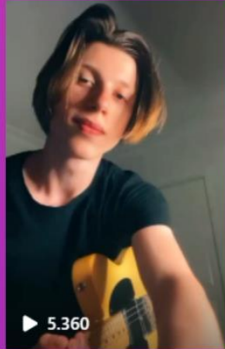
A question and answer event was organized with FMF Patient Kadir EZİLDİ. In particular, we aimed to show that patients with FMF are not alone and that they can make their voices heard more powerfully together with other patients.

Event statistics: 57,574 people participated.



The poster features a circular portrait of Kadir Ezildi, a man with glasses and a white shirt with red suspenders. The text on the poster reads: "Ekranların Sevilen Yüzü Kadir EZİLDİ ile Nadir İnsanların Nadir Hikayeleri Etkinliğinde Buluşmak Üzere." Below this, it says "Etkinlik Yayını: @gofteam.fmf" and "09.09.2021 Perşembe 21:00". There is a logo for "GOF TEAM" in the top right corner and a small icon of a person with a speech bubble in the bottom left corner.

SEPTEMBER STEAL FOR FMF TELL FOR FMF



SEPTEMBER - POSTER WORK



ERZURUM - KARAÇOBAN

SEPTEMBER - POSTER WORK



SIVAS

SEPTEMBER - POSTER WORK



SAMSUN

SEPTEMBER - POSTER WORK



KONYA - MERAM

KARAMAN

SEPTEMBER - POSTER WORK



ISTANBUL - ANKARA - BURDUR - BAYBURT

SEPTEMBER - POSTER WORK



ANKARA

SEPTEMBER – BROCHURE DISTRIBUTION



BOLU

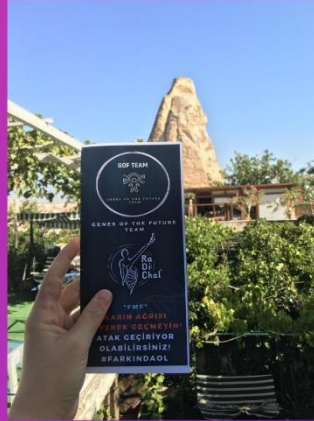


KARAMAN



SAMSUN

SEPTEMBER – BROCHURE DISTRIBUTION



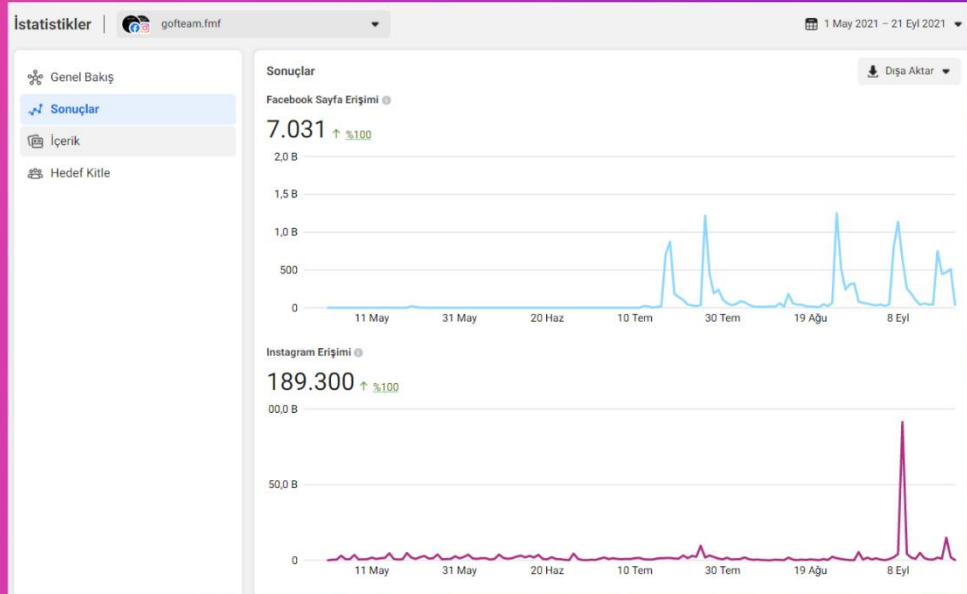
NEVŞEHİR

SEPTEMBER – BROCHURE DISTRIBUTION



SAKARYA

FACEBOOK AND INSTAGRAM ACCOUNTS DATA STATISTICS



INSTAGRAM ACCOUNT MONTHLY DATA STATISTICS



On 01.05.2021, an Instagram account was opened with the username gofteam.fmf to create social awareness. Informative content is shared on our account for FMF awareness. As of 01.05.2021, 1200 followers were reached on 30.05.2021. Statistically, the number of accounts accessed to our account is 28,850.



As of 30.06.2021, 1724 followers were reached. Statistically, the number of accounts accessed to our account is 25,369.



As of 31.07.2021, 2145 followers were reached. Statistically, the number of accounts accessed to our account is 24,709.

INSTAGRAM ACCOUNT MONTHLY DATA STATISTICS



As of 31.08.2021, 2347 followers were reached. Statistically, the number of accounts accessed to our account is 12,364.



As of 20.09.2021, 3011 followers were reached. Statistically, the number of accounts accessed to our account is 116,227.



As of 20.09.2021, 3011 followers were reached.

FACEBOOK ACCOUNT DATA STATISTICS



On 04.05.2021, a facebook page was opened with the username gofteam.fmf to create social awareness. Informative content is shared on our account for FMF awareness. As of 21.09.2021, 270 followers were reached. Statistically, the number of accounts accessed to our account is 7.031.

TWITTER AND YOUTUBE ACCOUNT DATA STATISTICS



On 01.05.2021, a twitter account was opened with the username gofteam_fmf to create social awareness. Informative content is shared on our account for FMF awareness. As of 21.09.2021, 206 followers were reached. Between 23.06.2021-21.09.2021, the number of accounts accessed statistically is 102,300.



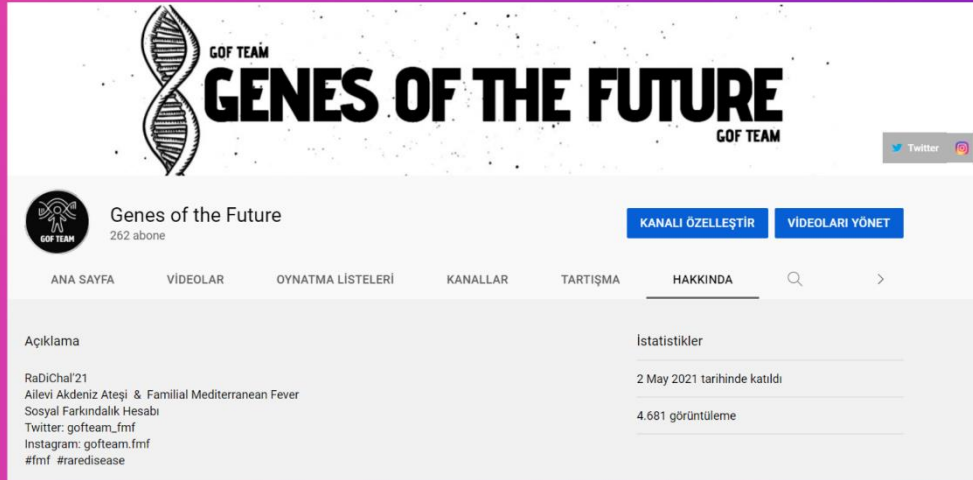
On 02.05.2021, a YouTube account was opened with the username Genes of the Future to create social awareness. Live broadcast events were organized on our account for FMF awareness. As of 21.09.2021, 262 followers were reached. Statistically, the number of accounts accessed to our account is 4,681.

TWITTER ACCOUNT DATA STATISTICS



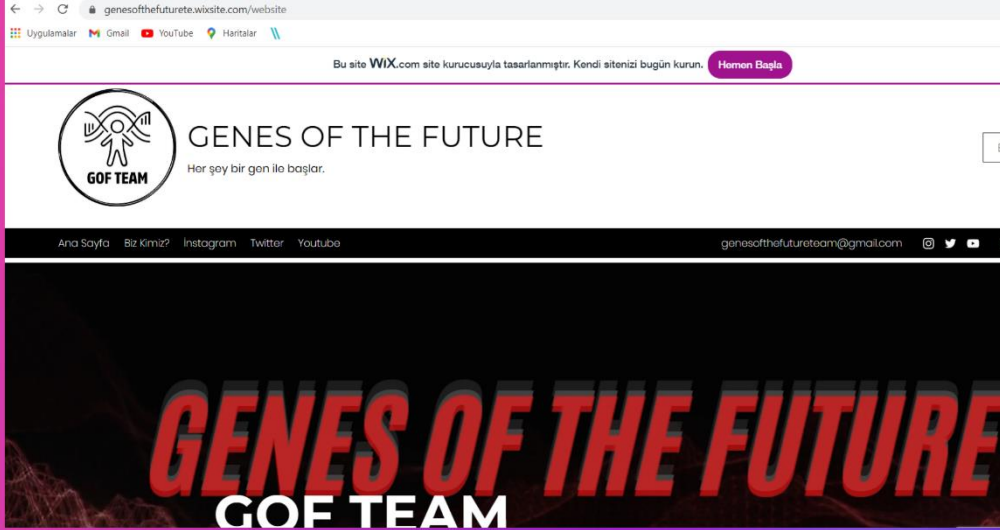
On 01.05.2021, a twitter account was opened with the username goftteam_fm to create social awareness. Informative content is shared on our account for FMF awareness. As of 21.09.2021, 206 followers were reached. Between 23.06.2021-21.09.2021, the number of accounts accessed statistically is 102,300.

YOUTUBE ACCOUNT DATA STATISTICS



On 02.05.2021, a YouTube account was opened with the username Genes of the Future to create social awareness. Live broadcast events were organized on our account for FMF awareness. As of 21.09.2021, 262 followers were reached. Statistically, the number of accounts accessed to our account is 4,681.

GENES OF THE FUTURE WEBSITE



As of MAY 2021, It can be accessed via the link <https://genesofthefuturete.wixsite.com/website>.

THE DECISION OF THE PROPOSAL TO THE MUNICIPALITY OF ANKARA – SINCAN



At the Ankara-Sincan Municipality City Council Meeting held on 02.08.2021, where we started negotiations in May, our proposal on "Social Awareness Study for Familial Mediterranean Fever Disease" was unanimously accepted.