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://sincanekspress.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-gecmayan-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-gecmayan-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

Figure 1. Poster Design

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

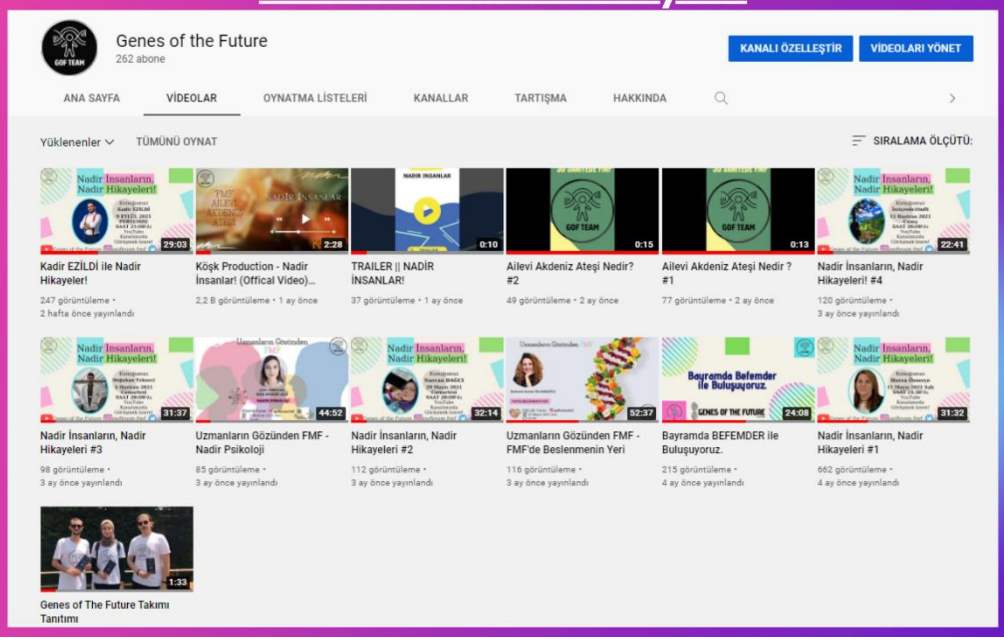
Figure 8. Bookmark Design 3- front side

Figure 5. Bookmark Design 1- back side

Figure 7. Bookmark Design 2- back side

Figure 9. Bookmark Design 3- back side

YouTube Account Layout



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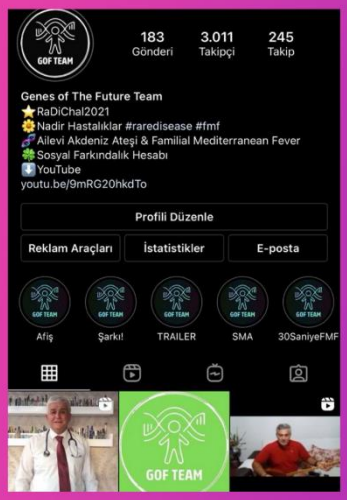

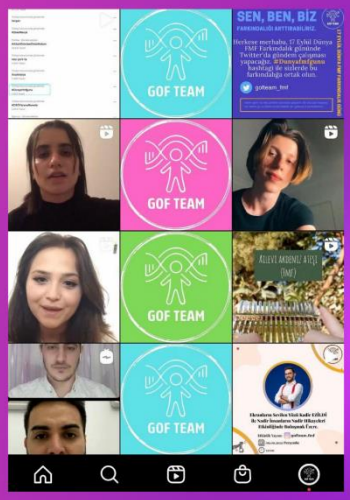

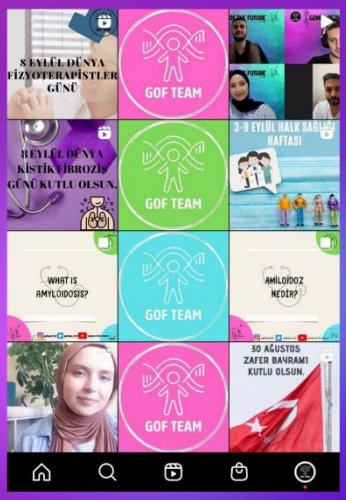

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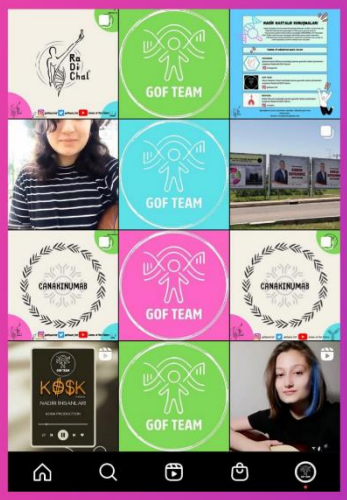

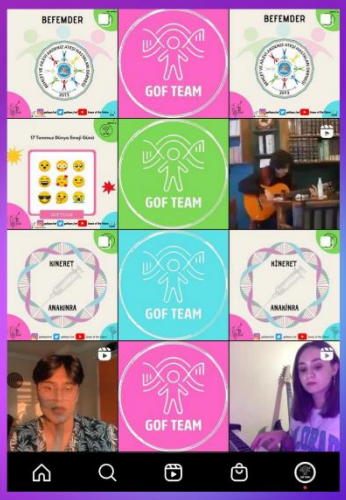

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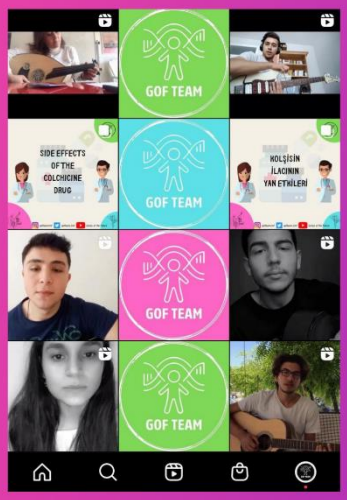

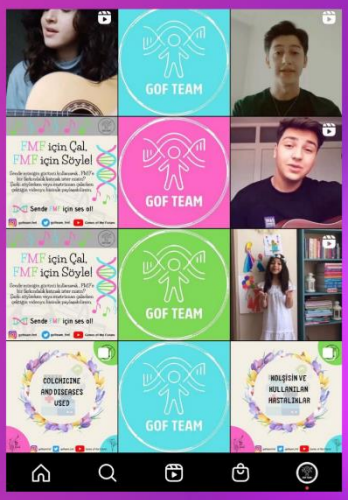

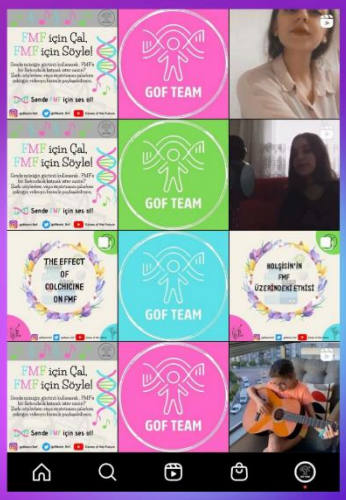

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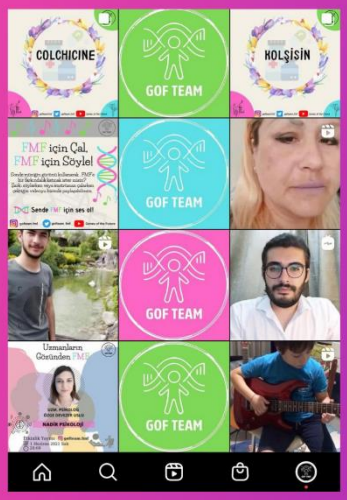

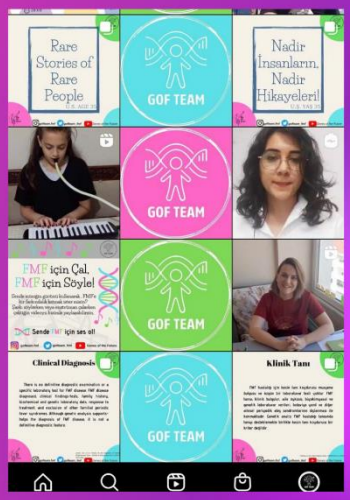

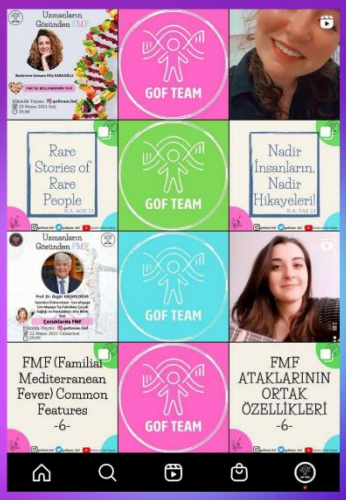

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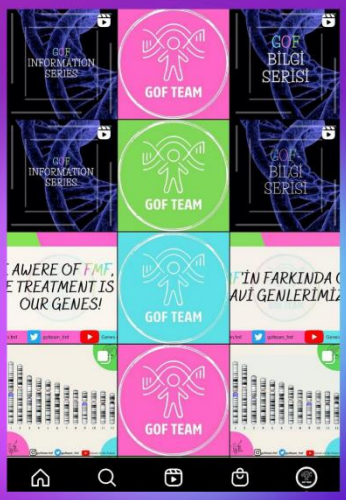

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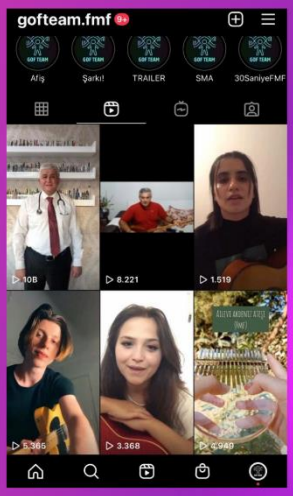

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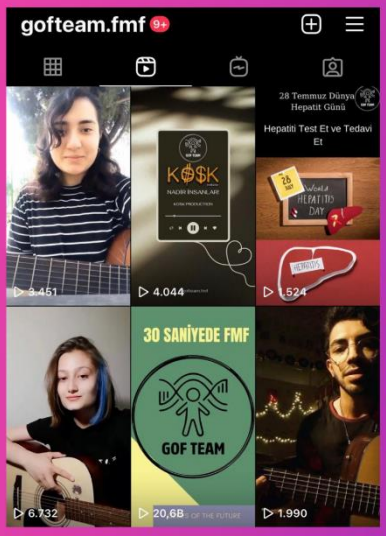

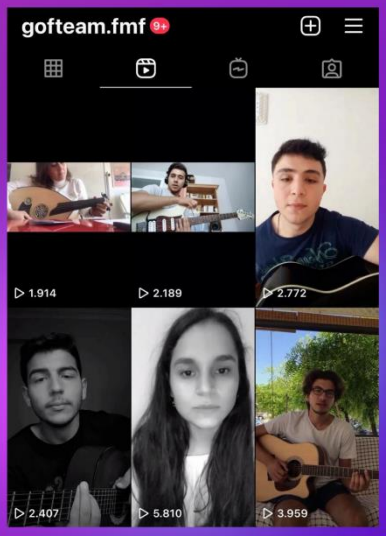

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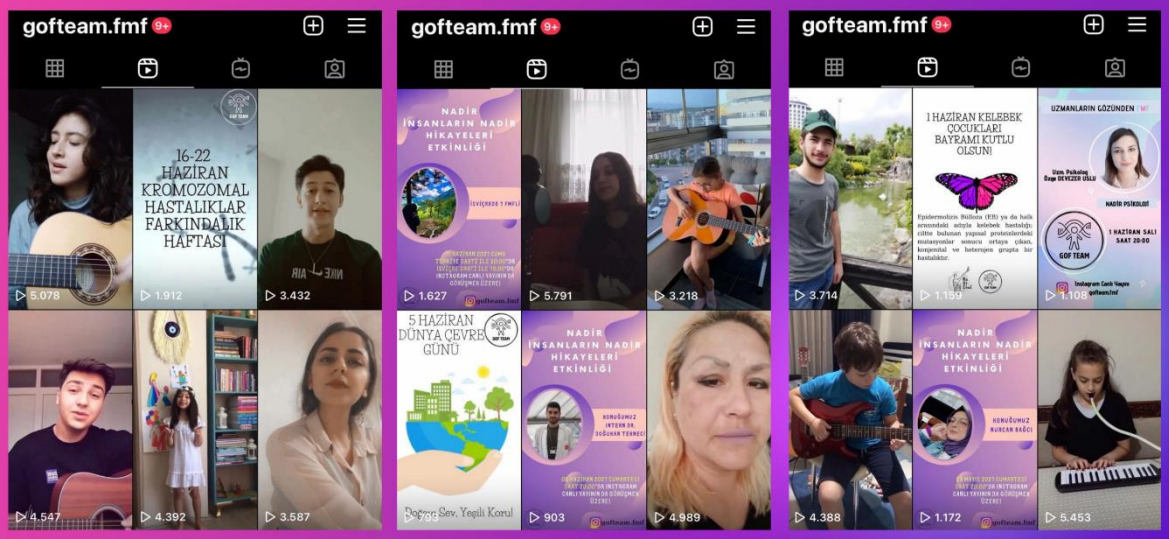

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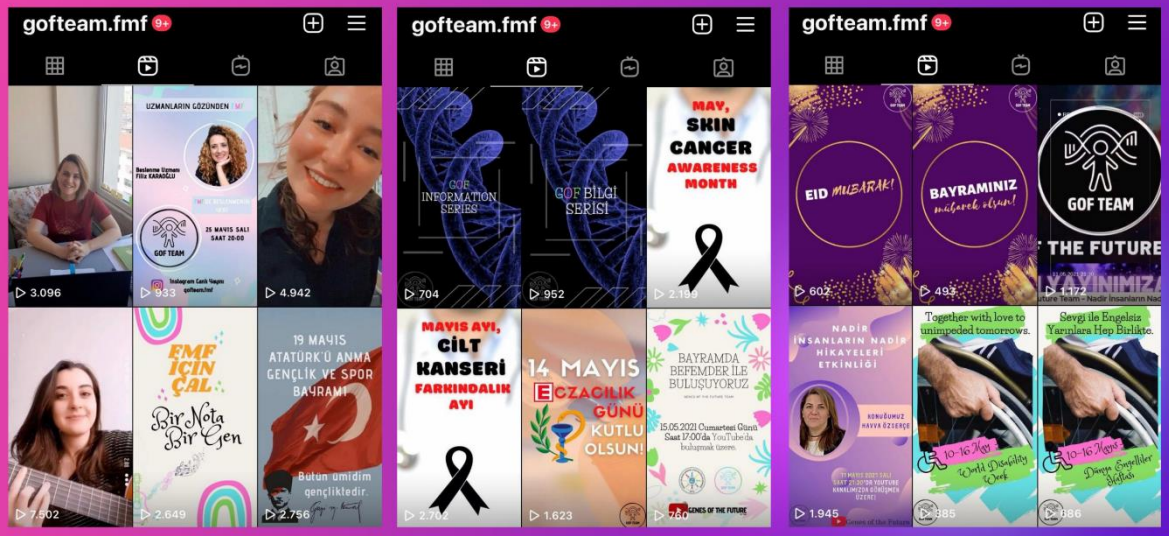

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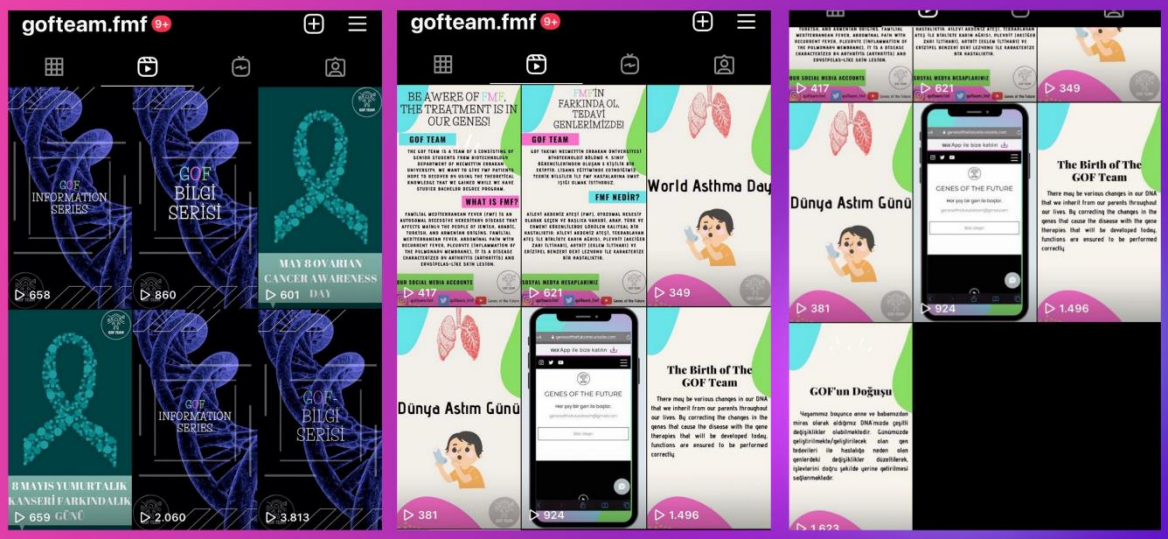

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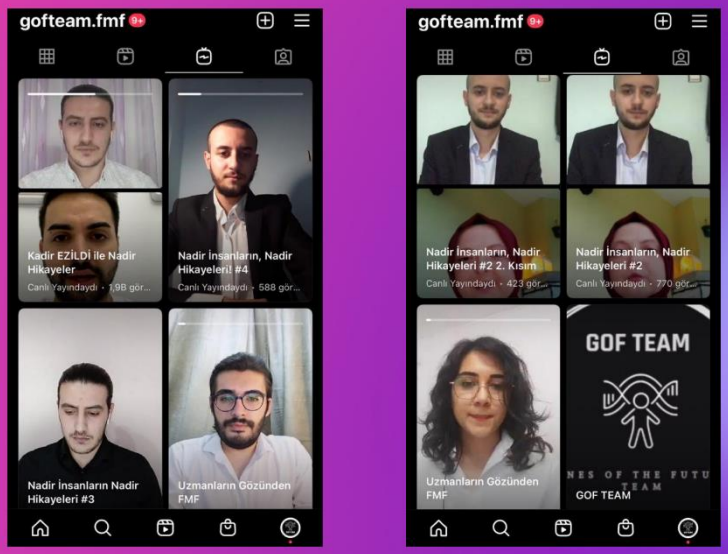

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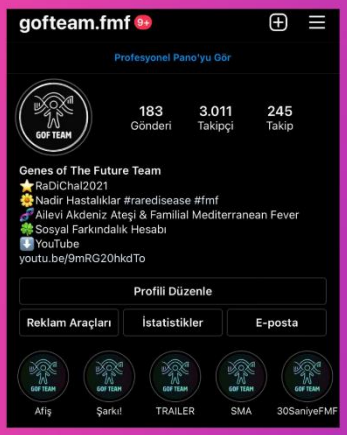

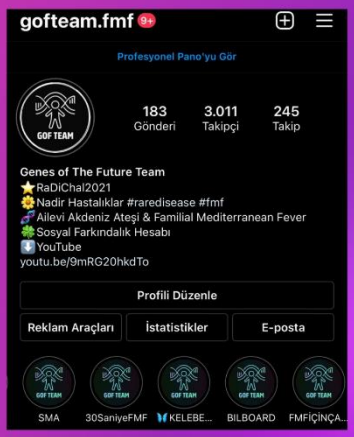

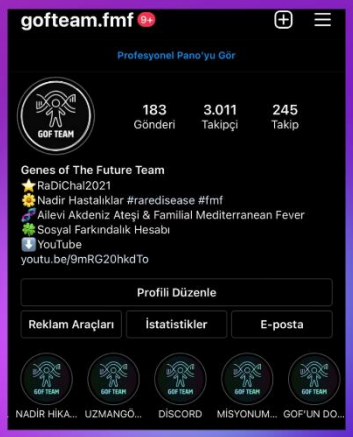

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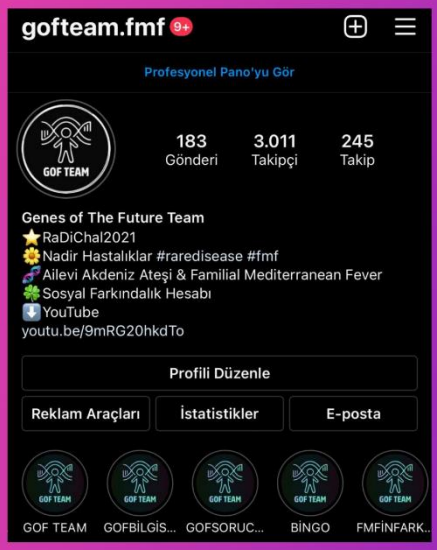
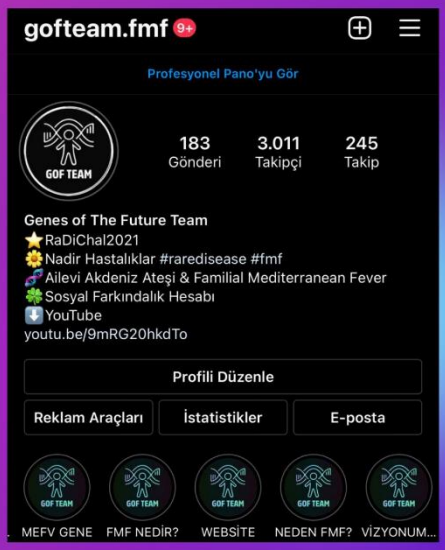




Event: Rare Stories of Rare People program

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 STORİES OF RARE PEOPLE EVENT WAS HELD ON YOUTUBE AND İNSTAGRAM LİVE BROADCAST WİTH FMF PATİENT 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

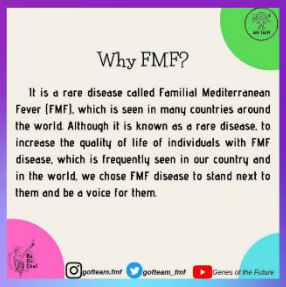
"WE ARE MEETING WITH BEFEMDER ON HOLIDAY!" EVENT

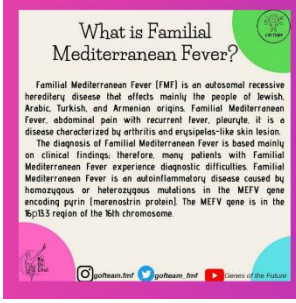
We realized our meetings with the BEFEMDER Association, introduced our group to the association on Saturday, 15.05.2021 at 17:00, and learned the mission and visions of the association, and understood their activities. In this live broadcast, information about the convenience and difficulties encountered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

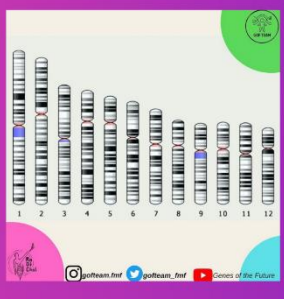
Event stats:
Number of live views : 71
Current view count : 215

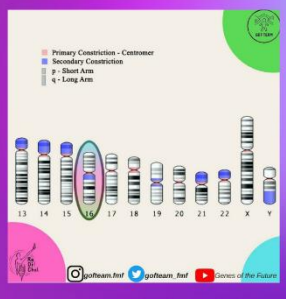
MAY STEAL FOR FMF TELL FOR FMF

CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN MAY









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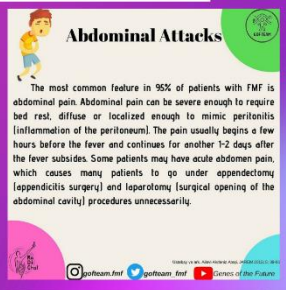

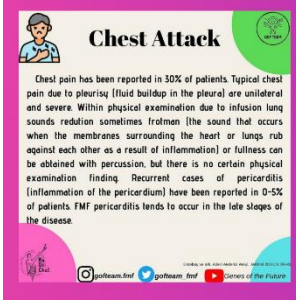

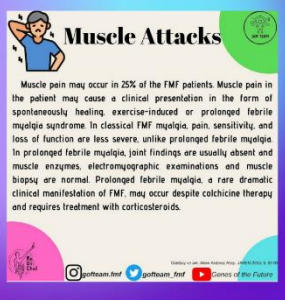

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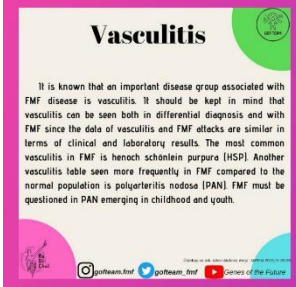

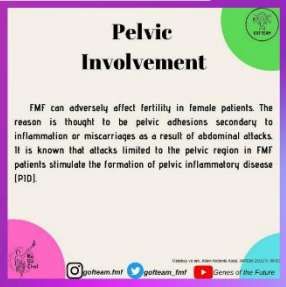

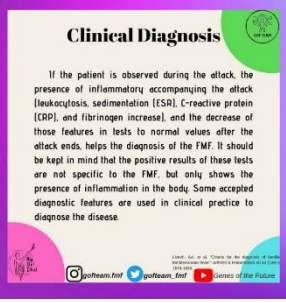

INSTAGRAM STORIES WE SHARED IN MAY

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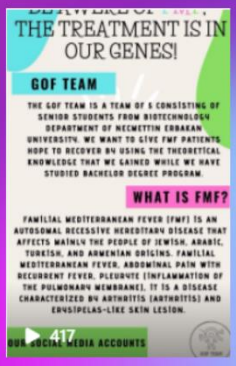
REELS VIDEOS WE SHARED IN MAY



REELS VIDEOS WE SHARED IN MAY

SHARE ON TWITTER IN MAY

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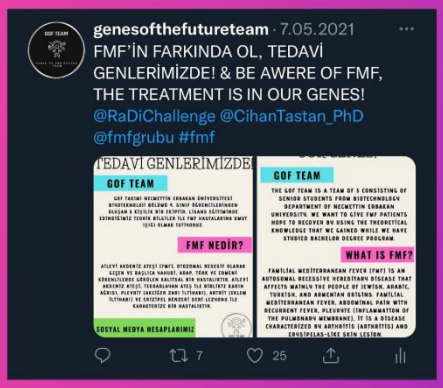


SHARE ON TWITTER IN MAY

ACTIVITIES WE CARRIED OUT IN JUNE

THE RARE STORIES OF RARE PEOPLE EVENT WAS HELD ON INSTAGRAM LIVE WITH FMF PATIENT DOĞUKAN 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.

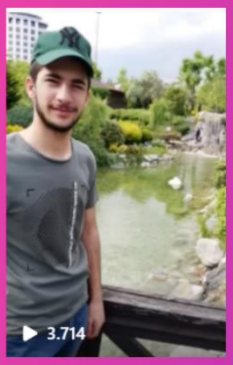
Event stats:
Number of Live Views : 153
IGTV views: 475
YouTube views: 98

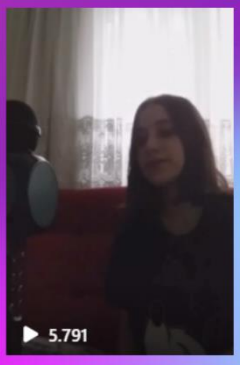
"RARE STORIES OF RARE PEOPLE!" EVENT

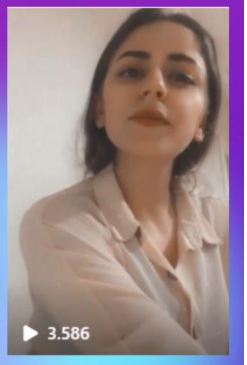
One of the other problems experienced by FMF patients is that the frequency and severity of attacks increase when colchicine is not used, and such patients remain dependent on colchicine for life. In patients resistant to colchicine, they use interleukin-1 inhibitor drugs. It was learned that the interviewed 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

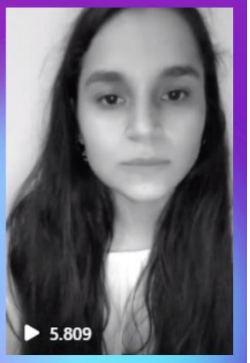
JUNE STEAL FOR FMF TELL FOR FMF



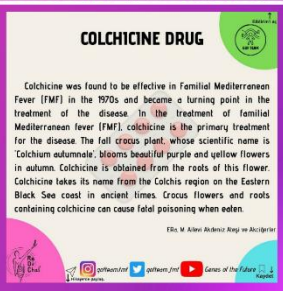


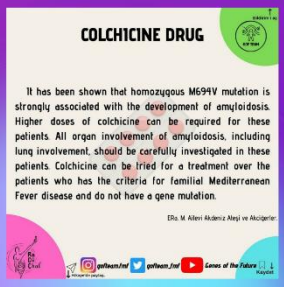


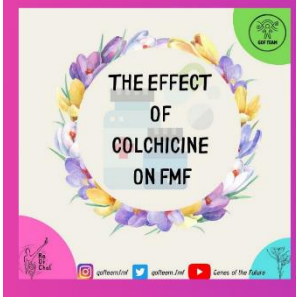
JUNE STEAL FOR FMF TELL FOR FMF

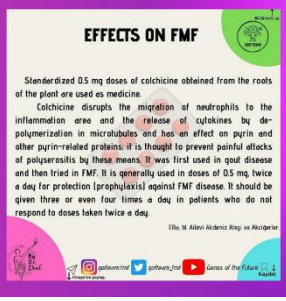


CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JUNE

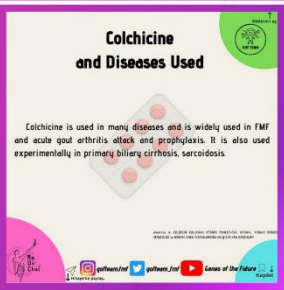


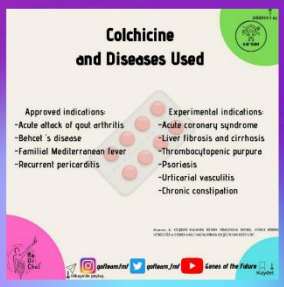


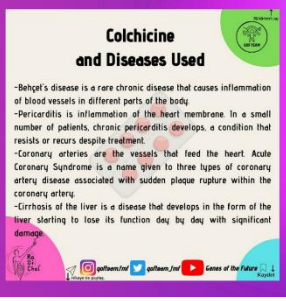


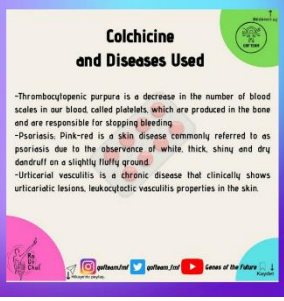


CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JUNE

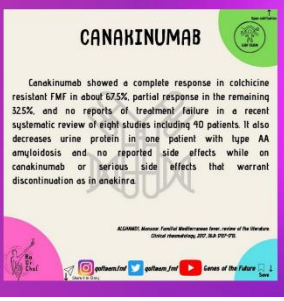








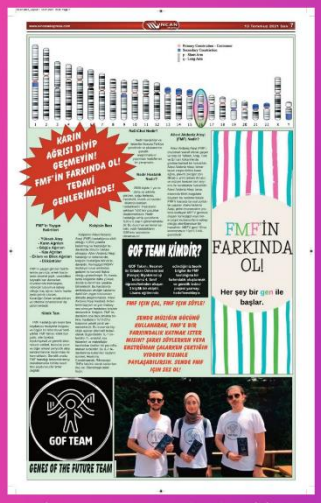
CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JULY



CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN JULY

INSTAGRAM STORIES WE SHARED IN JULY

ACTIVITIES WE TAKE IN JULY

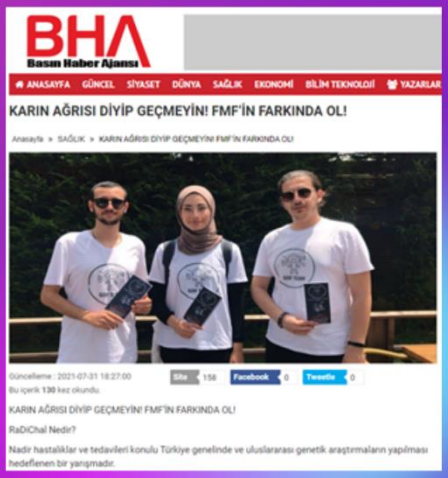


sincanekspress for familial Mediterranean fever -FMF- awareness newspaper 13 July 2021
They gave us a place in the 20th issue of the date.

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.

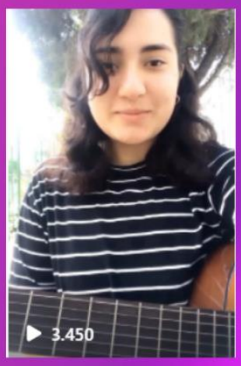
We prepared a video called FMF in 30 seconds and shared our video by briefly explaining FMF in 30 seconds.

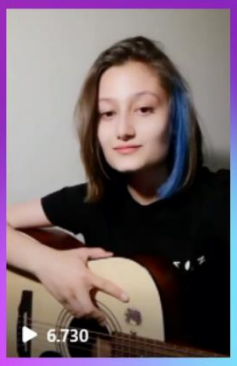
Link to our 'Rare People' awareness song: https://youtu.be/9mRG20hkdTo

JULY STEAL FOR FMF TELL FOR FMF

JULY STEAL FOR FMF TELL FOR FMF

JULY STEAL FOR FMF TELL FOR FMF

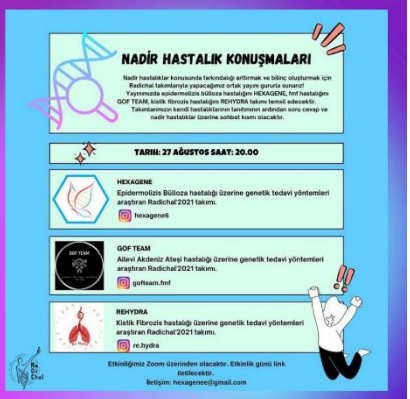




JULY - BROCHURE DISTRIBUTION

ANKARA - İSTANBUL

CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN AUGUST



REELS VIDEOS WE SHARED IN JUNE-JULY-AUGUST

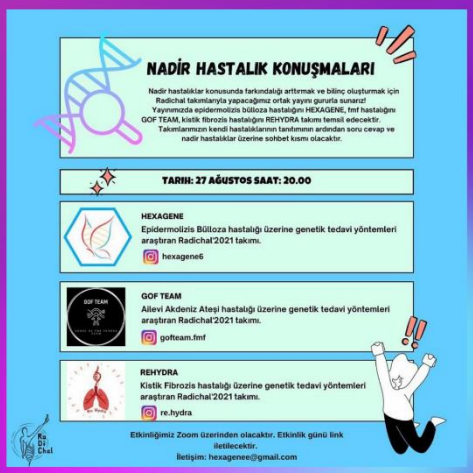
ACTIVITIES WE TAKE IN AUGUST

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

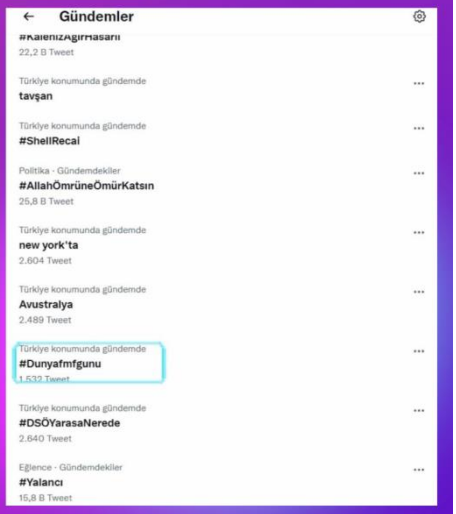
AUGUST - POSTER WORK

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

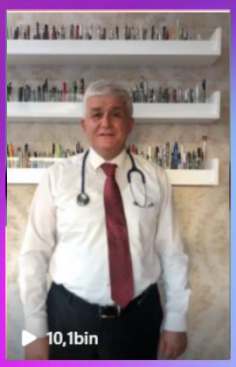
AUGUST - POSTER WORK

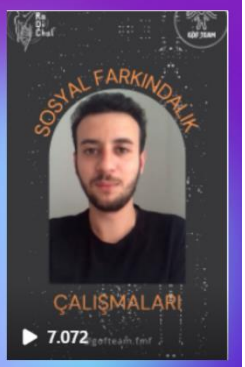
BURSA - KULTURPARK - ALTINPARMAK NEIGHBORHOOD- SELIMIYE NEIGHBORHOOD

CONTENT SHARED FROM OUR SOCIAL MEDIA ACCOUNTS IN SEPTEMBER



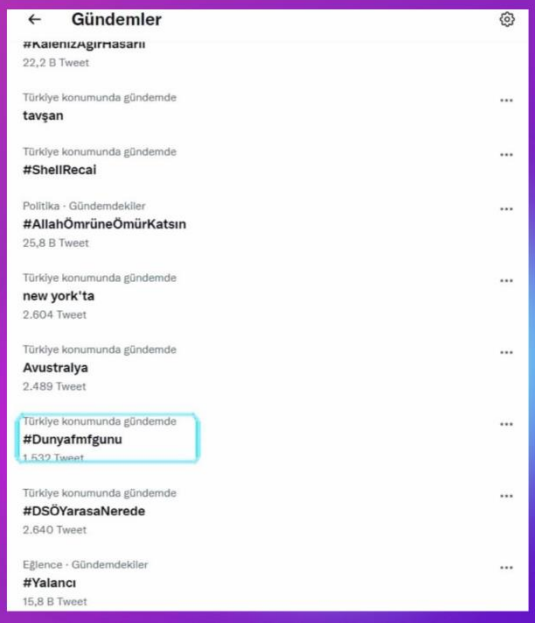
REELS VIDEOS WE SHARED IN SEPTEMBER



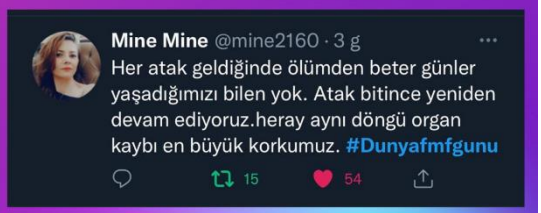


ACTIVITIES WE TAKE IN SEPTEMBER

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.



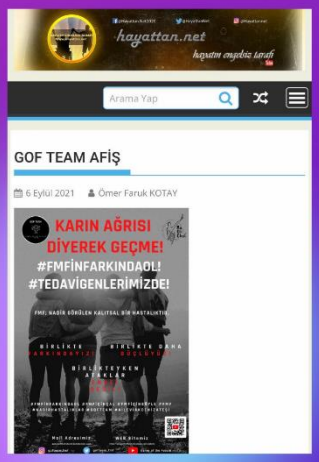
17 SEPTEMBER WORLD FMF DAY TWITTER AGENDA WORK



17 SEPTEMBER WORLD FMF DAY TWITTER AGENDA WORK

ACTIVITIES WE TAKE IN SEPTEMBER

Rare stories of rare people event with FMF Patient Kadir Ezildi was held on Instagram live broadcast.



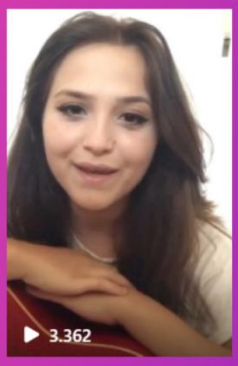
Our interview and poster design on Hayatdan.net has been published.

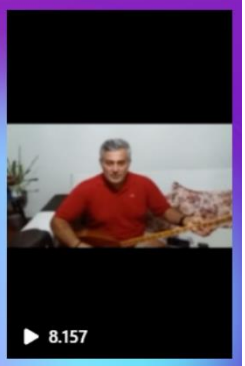
"RARE STORIES OF RARE PEOPLE!" EVENT

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.

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

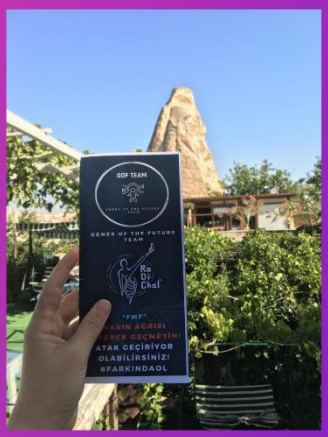
SEPTEMBER - BROCHURE DISTRIBUTION

BOLU

KARAMAN

SAMSUN

SEPTEMBER - BROCHURE DISTRIBUTION

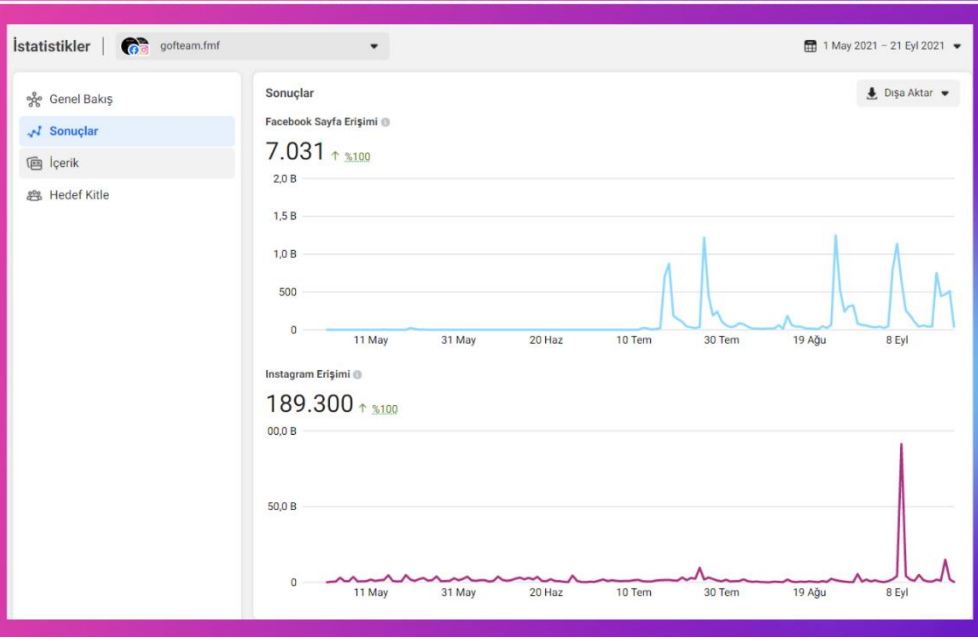


NEVŞEHİR

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.

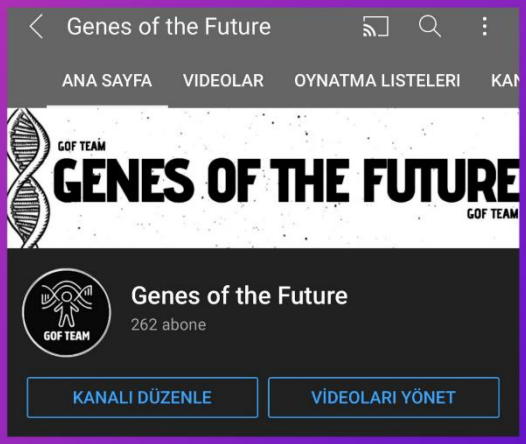
As of 20.09.2021, 3011 followers were reached.

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.

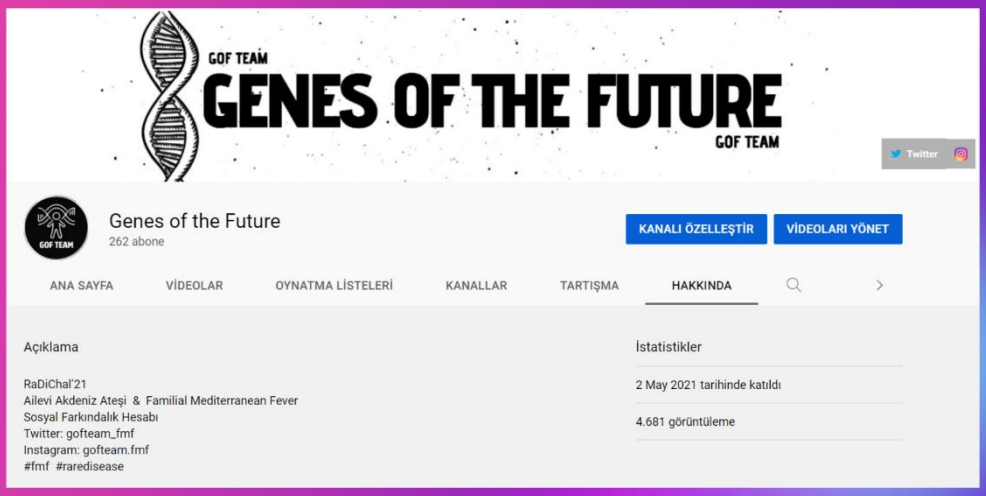


On 02.05.2021, a YouTube account was opened with the username Genes of the Future to create social awareness. Live broadcast events were organized on our account for FMF awareness. As of 21.09.2021, 262 followers were reached. Statistically, the number of accounts accessed to our account is 4,681.

TWITTER ACCOUNT DATA STATISTICS

On 01.05.2021, a twitter account was opened with the username 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.

YOUTUBE ACCOUNT DATA STATISTICS



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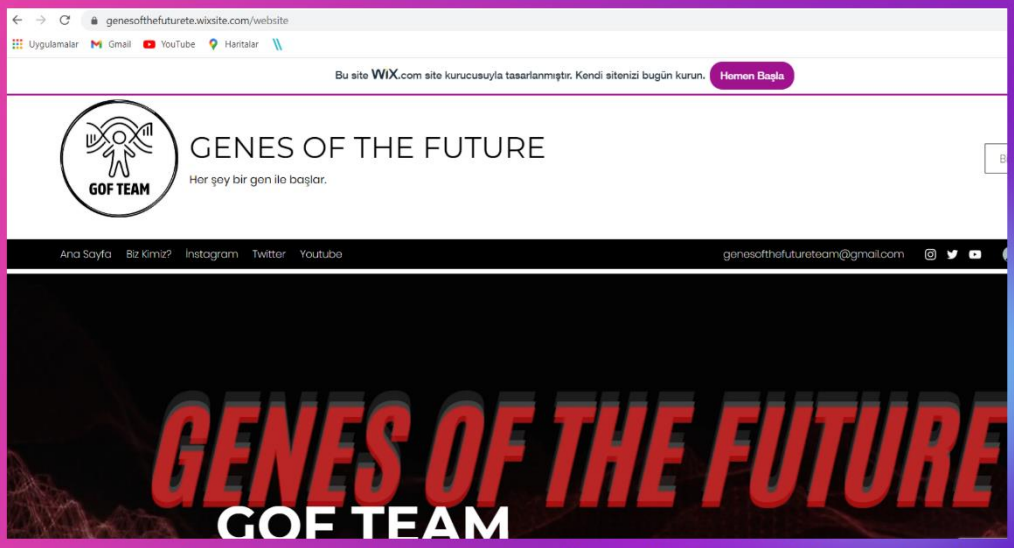
GENES OF THE FUTURE WEBSITE



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.