

# **RARE DISEASE CHALLENGE**

**RaDiChal'21**

Social Awareness Report

## **NAME OF THE GROUP**

The Mighty Chondrias

## **THE MEMBERS OF GROUP**

Başak Yerlikhan

Ersin Berkay Peker

Aslı Ceren Şimşek

Lamia Berra Akşit

Duygu Naz kutlu

## **TARGET DISEASE**

Familial Mediterranean Fever

- Social Media Account

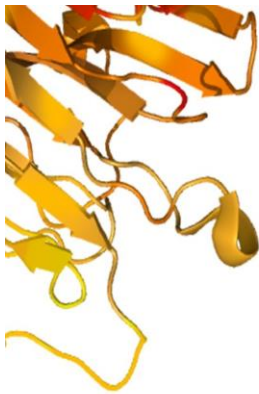
@themightychondrias

Followers : 24

Following : 136

Link : [https://instagram.com/themightychondrias ?utm\\_medium=copy\\_link](https://instagram.com/themightychondrias ?utm_medium=copy_link)

- Arrangement of the social media account



THE MIGHTY  
CHONDRIAS



**Figure 1 : The background of instagram posts**

In this figure, while big blank was left at the middle consciously, pieces of pyrin domain was placed on the left upper and right bottom corner. Therefore, there will be enough space for both information and attention was paid to the protein associated with the disease. By specifying our team name in a striking and eye-catching way in the lower middle part, we underlined the relevant group that carried out this work to the audiences that have been reached.

The posts were shared in both Turkish and English. In this way, we spread the information in a wider area and reach out the audience that follows us and wants to be informed.

In our posts, we have included information, campaigns and speeches we have organized, and patients' experiences in a way that is not tiring on the eyes, but attracts attention.

- Purpose and Timeframes of Our Sharings, Events
  - General information and speech was represented by Assoc. Dr. Şehime Gülsün Temel, which lasted for about 2 hours. The questions and answers were done via zoom by meeting with patients. Thus, we reached a group of people who do not know about the disease, but want to learn more, whether they are sick or not, and who have experienced it in their relatives. Notably, it was served for a useful purpose in which patients were also informed through the questions asked by the other listeners. There were even patients who joined to us from America in this presentation.

It was presented on 6 June 2021, at 10:00 am via zoom. More than 20 people reached out.



**Figure 2 : The moment of patient joining from USA asking questions and getting his answers.**

- Apart from that, a question and answer session was held with an individual whose daughter has FMF, and it was shared as IGtv on our social media account. The following questions were asked to her and her answers were received: How was the diagnosis made, How was the diagnosis process, What happens during the attack. This speech, which lasted 1 minute and 14 seconds, was shared on May 24, 2021.



**Figure 3 : The video containing Questions and answers of a follower whose daughter has FMF**

- The banner was prepared for the match between Beşiktaş and Adana Demirspor, we reached both the spectators in the stadium and the people on the screen. We aimed to both inform and support FMF. By this manner, we conveyed the competition, the disease and our work to more people. In the end, the support messages and questions we received from the audiences we reached made us even much happier and motivated.

This event, held on September 21, 2021, and shared on our social media account on the same date.



**Figure 4 : Familial Mediterranean Fever Awareness Banner**



**Figure 4.1 : Familial Mediterranean Fever Awareness Banner In The Stadium**

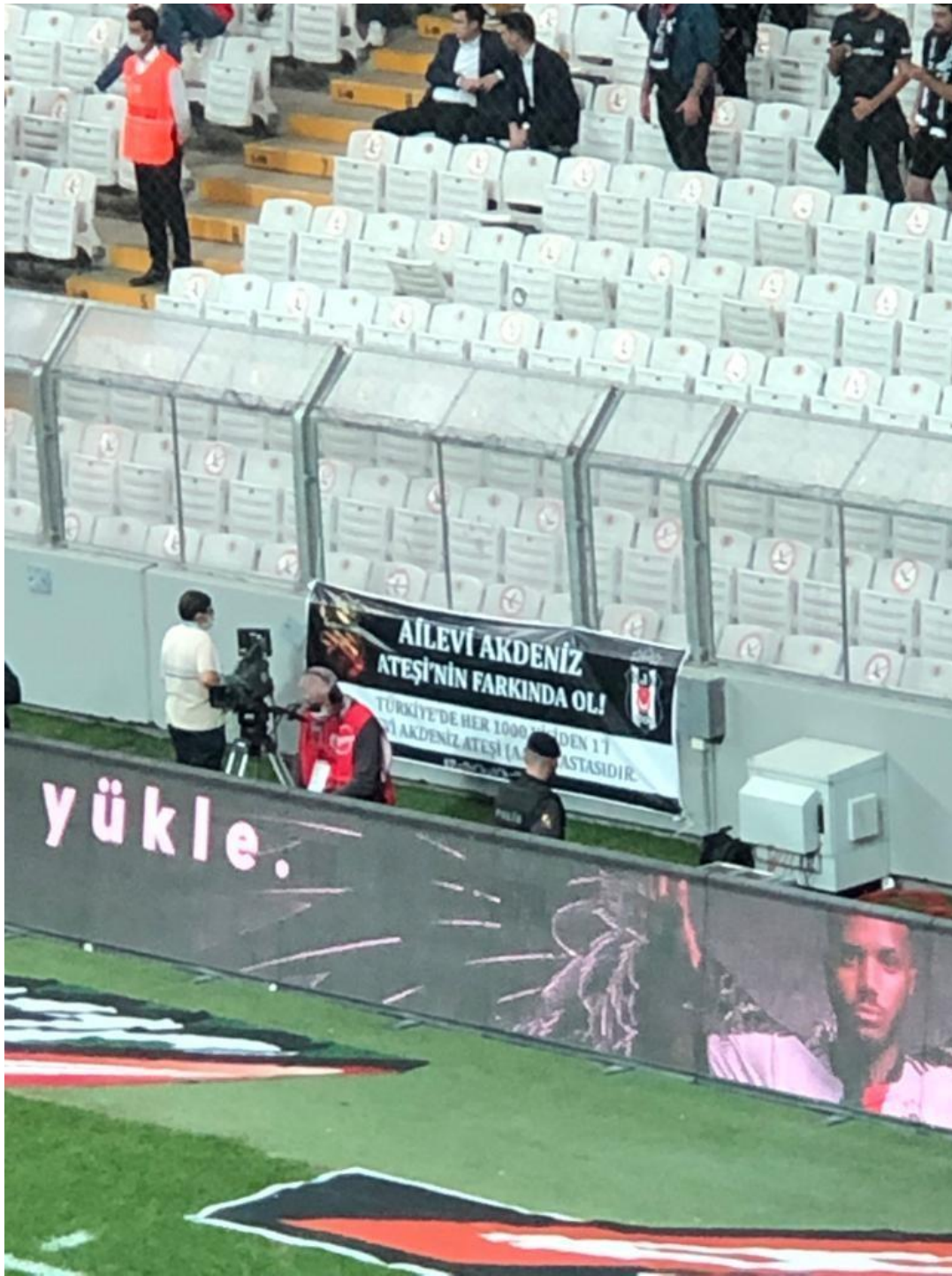
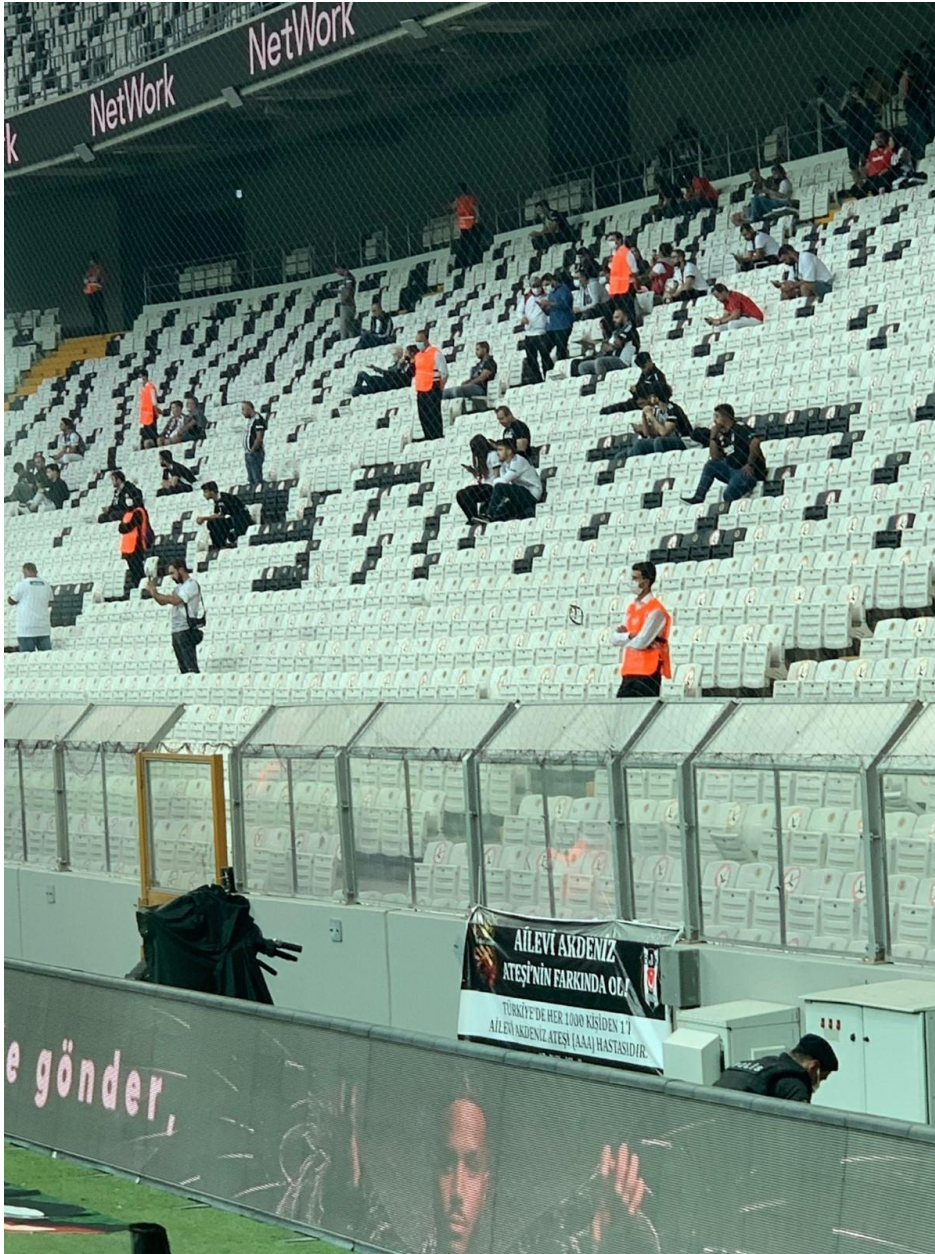
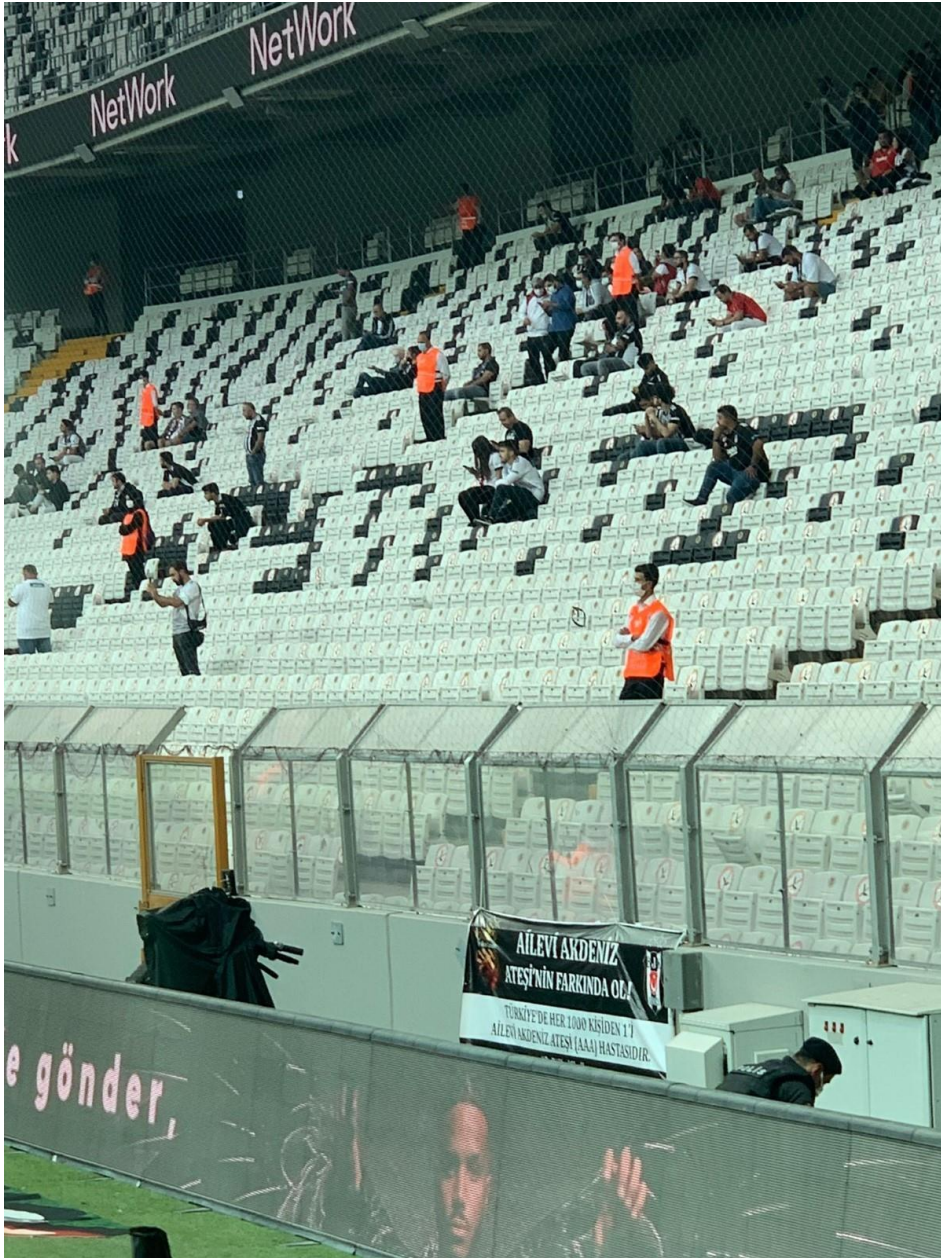


Figure 4.2 : Familial Mediterranean Fever Awareness Banner at the Stadium





**Figure 4.3 : Familial Mediterranean Fever Awareness Banner at the Stadium**



**Figure 4.4 : Familial Mediterranean Fever Awareness Banner at the Stadium**



**Figure 4.5 : Familial Mediterranean Fever Awareness Banner Viewed on TVs**

- A petition campaign has been launched for the FMF genetic screening test to be among the tests performed before marriage. Thus, it was underlined that although this disease counted as rare disease category, it is important and very common in Turkey, it is still not included in genetic screening tests.



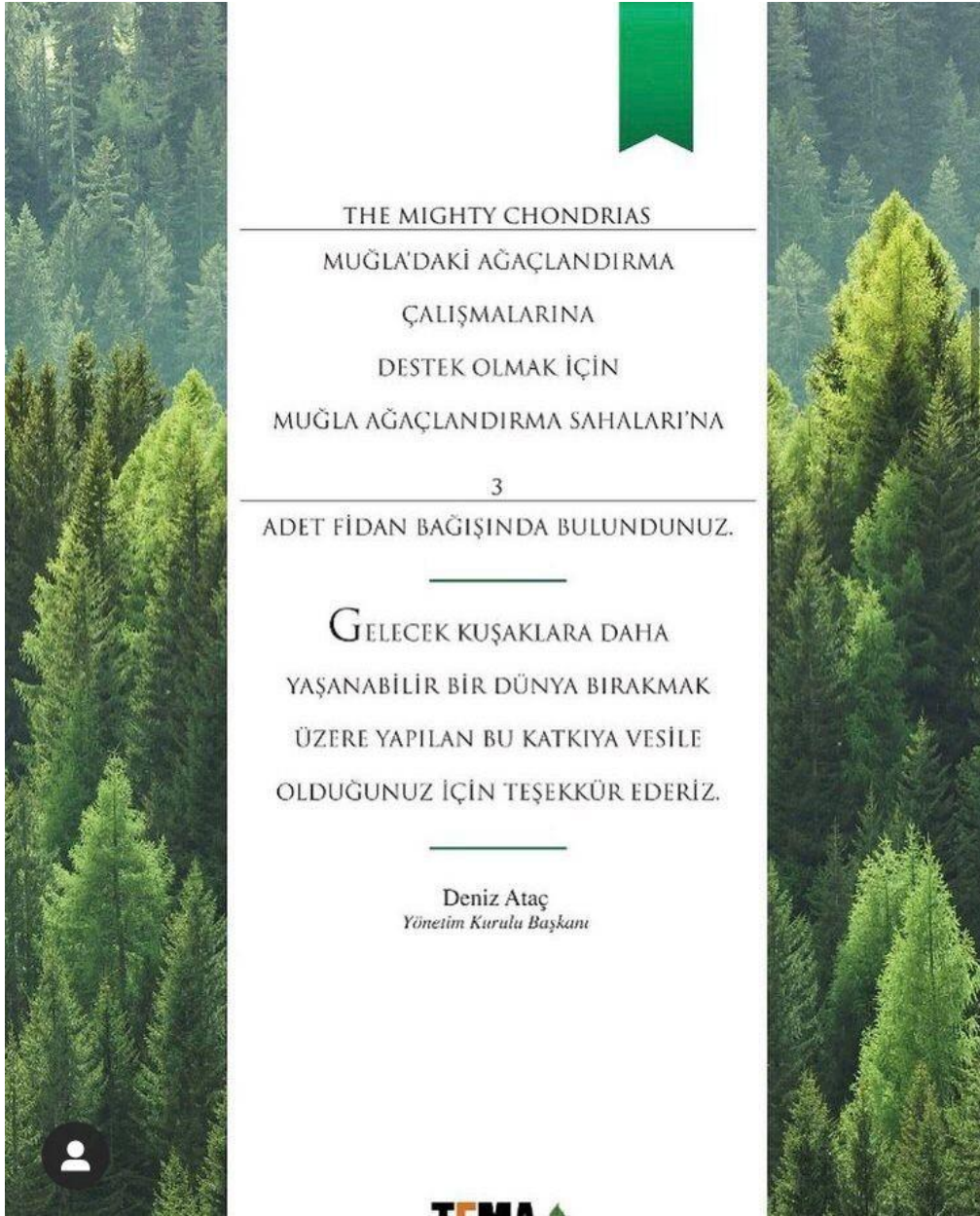
## AAA için genetik tarama testi evlilik öncesi yapılan testler arasında yer alsın

99 kişi imzaladı. Hedefimiz 100.

[Bu kampanyayı imzala](#)

Figure 5 : A petition campaign has been launched for the FMF genetic screening test

- The Mighty Chondrias, we ,donated saplings to TEMA in order to help our country heal its wounds in difficult days when forest fires increased. In this way, we took the first step as a team and directed other people to donate saplings and attracted attention. As a result, we aimed to create an FMF memory forest. We have contributed both to the lungs of our country and to the FMF disease. Our commemorative forest is still forming and donations continue to come. The campaign has been started on August 15, 2021.



**Figure 6 : The sapling donation and memorial forest formation process that we started as The Mighty Chondrias**

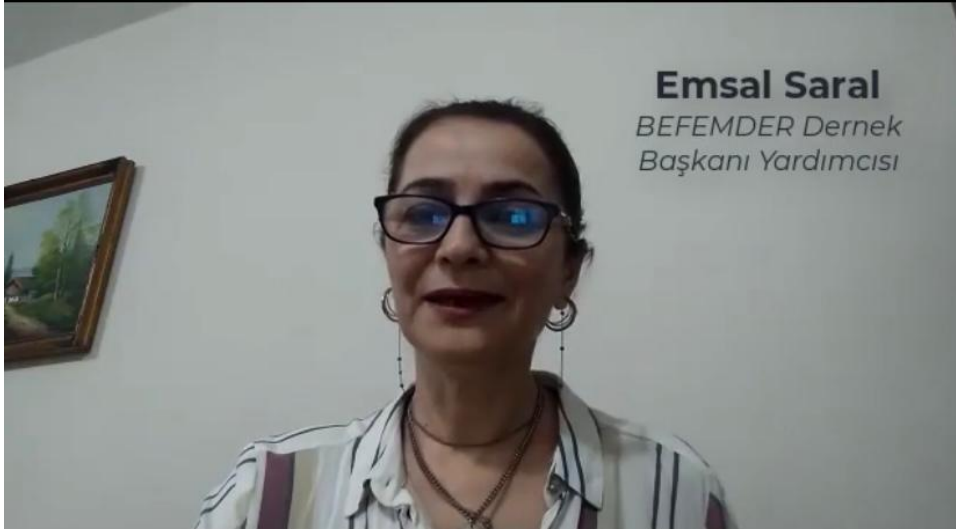
- The story of meeting BEFEMDER of one of our followers with Familial Mediterranean Fever was shared as an IGtv video. Thus, it was explained what should be considered in the diagnosis process and how to come together with other individuals with this disease after the diagnosis. In this way, we have announced this association, which is a common point of patients and doctors, to our followers.

This video was published on 27.09.2021 and takes a total of 5 minutes.



**Figure 7 : Our follower with FMF tells the story of meeting BEFEMDER**

- Emsal Saral, vice president of BEFEMDER association, gave information about BEFEMDER. This video was published on our account as IGtv. This video, which lasted 2 minutes and 23 seconds, was shared on 27.09.2021. Thus, it was mentioned what the duties of the association are, what it does, where it is and what they should do. In this speech, which also touched on the events organized by the association, we aimed to inform the masses we reached about the content of the association.



**Figure 8 : Emsal Saral, vice president of BEFEMDER association, is giving a speech giving information about BEFEMDER.**

- Another IGtv video has been published, in which our follower, who has FMF, tells about her experiences with the process. This video, which is 1 minute 55 seconds, was shared on our instagram account on 27.09.2021. Thus, an environment was created for those who are curious about the disease and patients, where they can share their knowledge and experience, as well as gain knowledge and experience.





