

# **RARE DISEASE CHALLENGE RaDiChal'21**

## **SOCIAL AWARENESS REPORT**

### **TEAM NAME**

**CysMode**

### **TEAM MEMBERS**

**Muhammed Fatih Kırçalı**

**Dilan Nisa Yılmaz**

**Gizem Gülfidan**

**Özge Önlütürk**

**Esra Yıldırım**

### **TARGET DISEASE**

**Cystic Fibrosis**

# SOCIAL AWARENESS ACTIVITIES

## 1. Social Media Accounts and Layouts

As the CysMode team, we have started our social awareness activities by opening social media accounts. We have reached several channels where we can introduce ourselves, primarily Instagram as well as Youtube and Twitter, and where we can conduct informative studies about rare diseases, especially Cystic Fibrosis. Below you can find the links to the social media accounts of our team.



@Cysmode RaDiChal'21

Link: [youtube.com/channel/UCg9OOGrePnW8xOyXrvQx4-g](https://youtube.com/channel/UCg9OOGrePnW8xOyXrvQx4-g)



@cysmode

Link: [instagram.com/cysmode/](https://instagram.com/cysmode/)



@CysMode

Link: [twitter.com/cysmode](https://twitter.com/cysmode)



Figure 1. Instagram Post Layout

As you can see in Figure 1 while sharing our Instagram posts, a triple system was developed and information and/or announcements were shared in plain but interesting colors.

On our Twitter account, a certain order was not followed, as we tried to support existing campaigns by re-tweeting or sharing about the TT's that were opened.

## 2. Activities and Studies

In the first month of the competition, in partnership with Podsonus Media, we carried out a podcast study to provide general information about Cystic Fibrosis and to reach the audience we could not reach. The podcast we created has been published by Podsonus Media on many social media platforms such as Youtube, Spotify and iTunes, and has expanded our awareness efforts by reaching audiences that we couldn't otherwise reach.



Figure 2. Event posters for May

In the second month of the competition, we decided to diversify our social awareness projects and had the opportunity to meet with our valuable academicians, who specialized in our target disease or who have conducted researches on Cystic Fibrosis, at our event called Rare Weekends with Cysmode. The first of these meetings was held on June 12.

Our first guest was Asst. Prof. Sonay Temurhan, with her genetic background, gave her doctoral thesis, "Investigation of the Relationship Between TGFB1 and CD14 Gene Polymorphisms and Disease Prognosis in Cystic Fibrosis Patient in the Turkish Population". In addition, on 13 June, under the same event, Prof. Dr. Didem Dayangaç-Erden from Hacettepe University Faculty of Medicine, told us about the Cystic Fibrosis studies that she has been continuing for a long time, together with the genetic basis, and the whole event was broadcast live on our Youtube channel. After the broadcasts, our live broadcasts are named as permanent videos on our YouTube channel and are made available to the public.

In addition to all these, he decided that it is essential for us to cooperate with other student clubs affiliated with our school, and our team member Int. Dr. Muhammed Fatih Kircali made a detailed presentation about the history, genetics and treatment methods of Cystic Fibrosis to the Young Doctors Worldwide Club of Marmara University. The presentation progressed by recruiting participants via Zoom and its recording was not published on any social media platform afterward.

Our work is followed and supported not only by our school and our social media accounts but also by KifDer, which provides a meeting place for Turks all over the world, especially patients and their relatives. They have expanded our audience by sharing the posters and announcements of our events on their social media accounts.

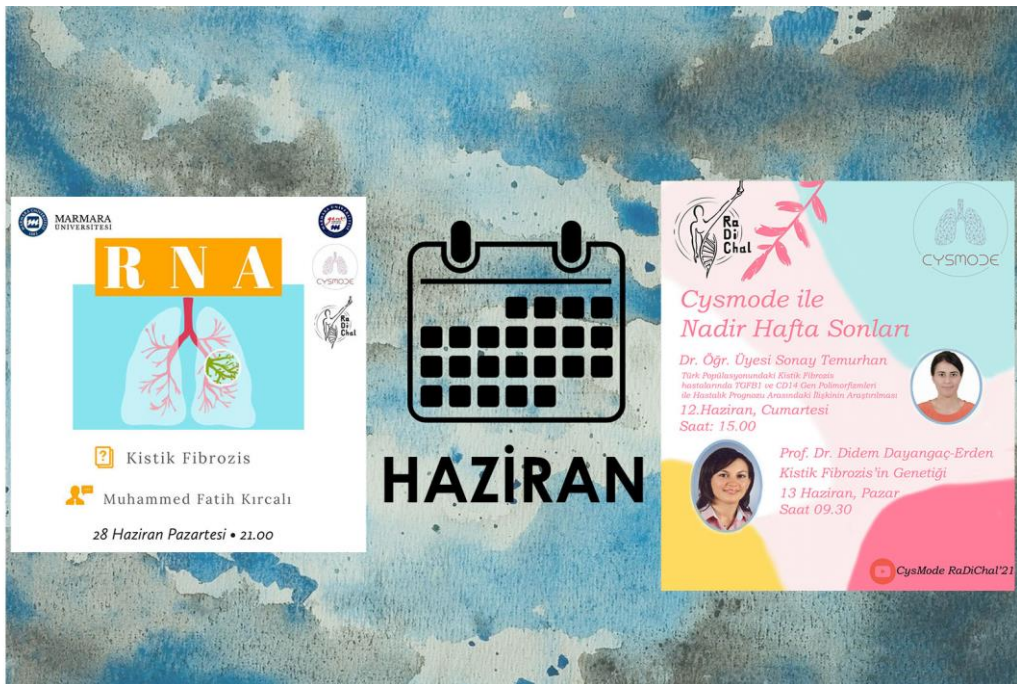


Figure 3. Event posters for June

In July, our social awareness activities continued at the same pace. In addition to our social media posts, to better understand the symptoms and physiological results caused by our target disease, we have held an event with Prof. Dr. Ender Dulundu from Marmara University Faculty of Medicine, Department of General Surgery, touched upon the Digestive System Problems in Cystic Fibrosis and gave a comment on the effects that have not been sufficiently addressed before.

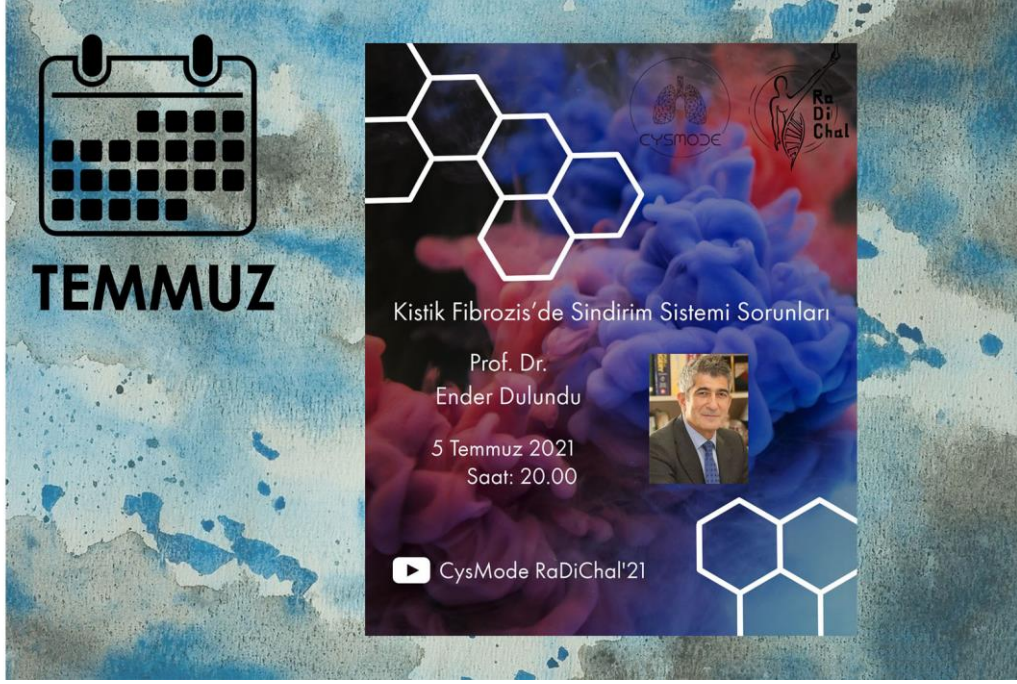


Figure 4. Event posters for July

In August, after the semi-finals were positive for our team, we continued to work on social responsibility projects. By actively using social media, we continued our informative activities without interruption; We have also shared information on social media channels, especially Instagram, to explain the genetics, treatments, effects, and symptoms of Cystic Fibrosis. Apart from this, our Zafer Bayramı on August 30, one of the most important milestones of our struggle for independence which we won under the Leader Atatürk, was celebrated with great enthusiasm on our social media accounts.

### 3. Statistics



Figure 5. Activity statistics for May



Figure 6. Rare Weekends with CysMode event statistics - 1



Figure 7. Rare Weekends with CysMode event statistics - 2

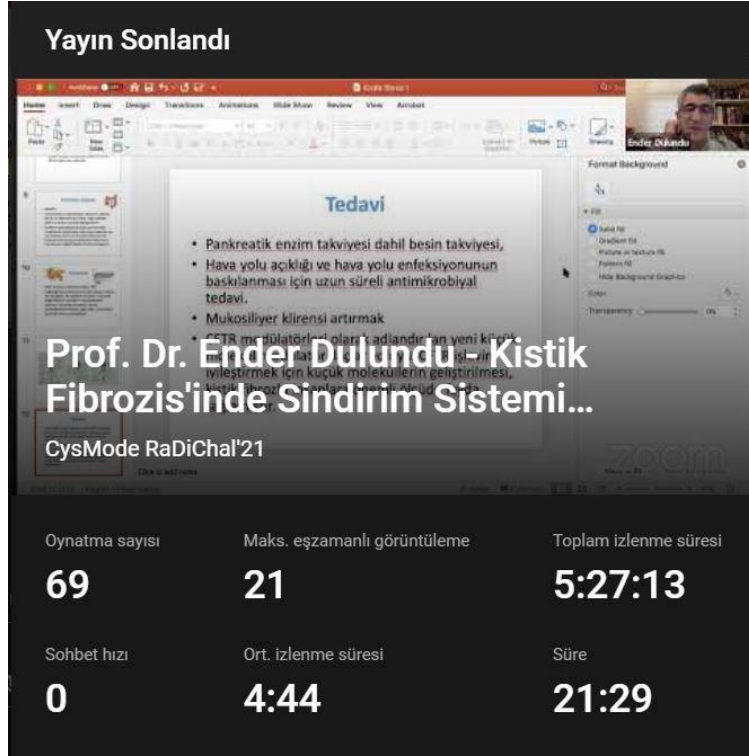


Figure 8. Prof. Dr. Ender Dulundu statistics