

### **Turkish Epilepsy Society**

2021-2022 Report

#### **CHAPTER OFFICERS**

Prof. Dr. Nerses Bebek, Chair Prof. Dr. Sibel Velioglu, Vice chair Assoc. Dr. Aylin Bican Demir, Secretary General Prof. Dr. İbrahim Oztura, Treasurer Prof. Dr. İrem Yildirim, Member Prof. Dr. Yasemin Bicer Gomceli, Member Dr. Ayşe Deniz Elamli Yazici, Member



Officer Election Date: 28 May 2022

### **ACTIVITIES AND ACCOMPLISHMENTS**

- Scientific Meetings and Courses:
  - o 21 January 2022: Turkey Epilepsy Pregnancy Study Results
  - o 18 February 2022: Sexual Dysfunctions in Epilepsy
  - o 21 October 2022: Epilepsy and Exercise
  - o 23 December 2022: Review of the New Epilepsy Syndrome Classification
  - 31 March 2022: ILAE Chapter Symposia: Prof. Dr. Helen Cross and Prof. Dr. Ömer Hakan Emmez: "Hypotalamic Hamatoma", online
  - o 21 January 2021: "VNS therapy in drug-resistant epilepsy"
  - 25 February 2021: "Future directions of neuroscience and epilepsy workshop"
  - o 30 April 2021: "Epilepsy-and dementia beyond our knowledge", online
- Support for projects and scholarships was created in the field of epilepsy.
- Training videos were prepared on the social media network.
- March 2022 world epilepsy day event was held. Bridges in Istanbul were illuminated in purple. A run was arranged for epilepsy. Written and verbal messages were given in sports activities.
- Negotiations were held with the officials of the Ministry of Health regarding the driver's license. Physicians were informed.

#### FEBRUARY-MARCH 2022 INTERNATIONAL EPILEPSY DAY & PURPLE DAY

On the International Epilepsy Day in 2017, as the Turkish Chapter of the International League Against Epilepsy, we launched the #LookForEpilepsy awareness campaign for the first time with the unconditional support of UCB Pharma.

The #LookForEpilepsy Awareness Campaign aims to raise social awareness that people living with epilepsy can continue their lives, read, work, marry, have children, and achieve successful jobs like everyone else.

While the campaign was created, purple, the global color of epilepsy, was combined with the glasses icon, which represents changing the prejudiced perspective. The Purple Glasses icon was used both on the field and on digital platforms to represent epilepsy awareness and everyone was invited to leave their prejudices against epilepsy behind. By extending the timing of our campaign to cover the International Epilepsy Day and the Purple Day, we continue to raise awareness and fight against the prejudices about epilepsy with our unconditional supporter UCB Pharma Turkey.

While conducting the #LookForEpilepsy awareness campaign in 2020 and 2021, we created different concepts and shared a lot of posts related to the theme throughout the year. #YIIOImuş2020/#InThisYearAndAge in 2020 "There are still people who think that epilepsy is contagious and that people living with epilepsy cannot get married and work!" Our campaign gained strength with those messages, and prejudices were handled with witty criticism. In the year 2021, with the concept of #WhatDoesItHaveToDoWith, the messages we focused on "#WhatDoesItHaveToDoWith not being able to study, work, become successful in business life, get married or have children, and being contagious!". We drew attention to these matters and explained that people living with epilepsy can live as a part of society like everyone else through our social media posts.

In the year 2022, we built on the "teaching epilepsy from scratch" concept with #LongStoryShort |#UzunLafınKısası hashtags aiming to break down prejudices by teaching the truth: "#LongStoryShort | #UzunLafınKısası, people living with epilepsy can study, be successful in business life, marry, and have children like anyone!". The volunteer campaign ambassador in 2022 was the famous Turkish actor Furkan Andıç.

We run the #LookForEpilepsy awareness campaign simultaneously on multiple channels with a 360-degree communication approach.

For the campaign that started on World Epilepsy Day, we shot 3 awareness films with Furkan Andıç, which include valuable information about epilepsy. Our films have been watched 1.860.000 times in total. Many celebrities, artists, influencers, physicians, journalists, municipalities, and sports clubs shared these films via their social media accounts and supported epilepsy awareness and our campaign.

While the main channel of the awareness campaign was Instagram, other social media channels and digital channels were also actively used. We designed a new Purple Glasses Instagram filter, and we presented it to social media users, drawing attention to the #LongStoryShort theme. The Purple Glasses Instagram filter has been viewed 108.350 times in total.

A page with the theme #LongStoryShort has been launched on the website landing page; <u>https://www.epilepsiicinbak.com/uzun-lafin-kisasi</u> access the right information on the internet, to increase awareness and to access the works of the previous years' archives on the www.epilepsiicinbak.com.

Fatih Sultan Mehmet and Yavuz Sultan Selim Bridges, two of the symbols in İstanbul, were illuminated with purple light on 17 February 2022 as part of the International Epilepsy Day activities with our efforts.

The popular TV series "Yargı" owned by an Ay Yapım media organization, shared our campaign messages on the International Epilepsy Day. In the 20th episode "Prosecutor Pars", who played a character living with epilepsy, said, "People living with epilepsy can work and be very successful in their jobs and they continue their normal lives.". Whereas our campaign messages were given related to the follow-up of the disease of epilepsy patients in the doctor's scene from the episodes added to the series with the initiatives of the #LookForEpilepsy|#PurpleGlasses Awareness Campaign, in the episode where the character of "Prosecutor Pars" made a press statement, it was underlined that epilepsy would not prevent working and being successful in business life.

On the popular YouTube program with millions of views, "Tonight Show with İbrahim Selim", the program crew supported our awareness campaign by wearing purple glasses. The episode in which purple glasses were worn was watched by 475.743 people.

In a video of our campaign, volunteer campaign ambassador Furkan Andıç inviting everyone to awareness of epilepsy was broadcast on TV screens in public vehicles, which are used by millions of people every day in Istanbul. The campaign video was on the screens of buses, metro buses, subways, and ferries for 36 hours and reached 6 million people from 8.500 screens.

During the second week of February, Istanbul Sapphire Shopping Mall and Özdilek Park İstanbul shopping mall published our campaign messages on their LED screens, and also they shared them on their Instagram pages.

Turkish Basketball Federation voluntarily supported our campaign by posting messages on LED screens in the top leagues' games. Our messages were displayed in the stadiums during the competitions played in the ING Basketball Super League and Herbalife Nutrition Women's Basketball Super League.

This year lots of football teams supported our campaign again! Beşiktaş Football Team unfurled a "Look for Epilepsy" banner at the stadium during the Spor Toto Super League match played against Altay Spor Club on February 19, 2022, at Vodafone Park. Another football club Ittifak Holding Konyaspor appeared in the Spor Toto Super League match, which was played against Kasımpaşa Football Club on February 18, 2022, with the banner "Be Aware, Support, Look for Epilepsy."

Trabzonspor Football Team players Hüseyin Türkmen, Berat Özdemir, Yunus Mallı, Uğurcan Çakır, and Edin Vişça shot a video for the #LookForEpilepsy Awareness Campaign, in which they

gave meaningful messages with our purple glasses. Their #LongStoryShort and #LookForEpilepsy-themed messages attracted great attention from social media users.

Dugun.com, which is a frequent destination for couples entering the marriage process, supported our campaign with the message that "1 out of every 5 people do not want their relatives to marry an individual with epilepsy. People living with epilepsy can love, get married, and have children."

Cooperation was performed with the most popular bookstore in Turkey, Nezih Kitap-Kırtasiye. We created a bookmark with includes an epilepsy story. A total of 8,150 bookmarks were distributed free of charge in 31 stores. Also, they supported our campaign by sharing posts on their social media account.

Datça, Çanakkale and Maltepe Municipality, and many others on Twitter shared their awareness messages about epilepsy and supported the #LookForEpilepsy.

Furthermore, the media relations activities were carried out within the scope of International Epilepsy Day on February 14 and Purple Day on March 26. Regarding 10 press releases were served on media.

On 24 March 2022, we came together with prominent press members in an online press conference. The press release, we published after the meeting. A total of 1,176 news were published on online channels. Our campaign was featured in 60 print media news, appeared on Fox TV Merve Yıldırım ile Benden Söylemesi, Fox TV Çalar Saat İsmail Küçükkaya, Beyaz TV Söylemezsem Olmaz, TV100 Var Odası, Beyaz TV Beyaz Futbol, Show TV Cumartesi Sürprizi, TV NET 4x4 Futbol and on many other programs and on 17 TV news. 1 million 545 thousand TL advertising equivalent was achieved. 4,332,564 people were reached.

Furthermore, within the scope of Purple Day, Galata Tower, İzmir Clock Tower, Gaziantep Castle, and Amasya Castle were illuminated with purple lights, the color of epilepsy.

On Purple Day, 26 March 2022, Istanbul-Maltepe Municipality organized a seven-kilometer awareness run with #LookForEpilepsy logos purple t-shirts, and UCB and Turkish Chapter Of the International League Against Epilepsy support.

With these efforts, we made visible in digital media and traditional media. Our awareness videos reached 55 million potential views on digital channels with FB, Twitter, and Instagram.

We prioritize the sustainability of our efforts to spread the awareness of epilepsy and to eliminate the prejudices faced by people living with epilepsy... Even though we take many awareness steps, for this reason, your contribution will always add value.

If you would like to support the #LookForEpilepsy Awareness Campaign, you can use the #PurpleGlasses filter on the @epilepsiicinbak Instagram page to take your photos, share your awareness messages, and post them using the hashtags #LookForEpilepsy and #LongStoryShort Hope to see each other on healthy and unprejudiced days...

#### **FUTURE PLANS FOR 2023**

- Epilepsy symposium, 26-28 May 2023
- National Epilepsy Congress of Turkish chapter of ILAE, 2024
- Educational activities, EEG, webinar meetings epilepsy course

### **RESEARCH AND PUBLISHED ARTICLES**

The Turkish epilepsy journal continued its publications regularly. "Arcihes of epilepsy'

#### **MEETINGS**

- Meeting: National Epilepsy Congress was held face to face 26-29 May 2022.
- As a result of the election held in our ordinary general assembly on 28 May 2022, we also determined our new board of directors and supervisory boards. Our new board of directors and the distribution of duties are as follows:
  Prof. Dr. Nerses Bebek Chair
  Prof. Dr. Sibel Velioglu Vice chair
  Assoc. Dr. Aylin Bican Demir Secretary General
  Prof. Dr. İbrahim Oztura Treasurer
  Prof. Dr. Yasemin Bicer Gomceli –Member
  Dr. Ayşe Deniz Elamli Yazici Member
- National Epilepsy Congresses were held between 27-30 May 2021, online.



Bridges in Istanbul were illuminated in purple. A run was arranged for epilepsy. Written and verbal messages were given in sports activities.





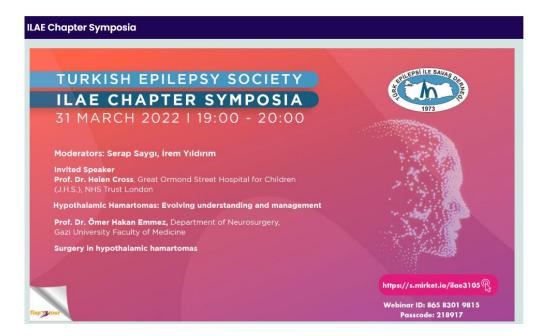
The National Epilepsy Congress was held face to face between 26-29 May 2022.





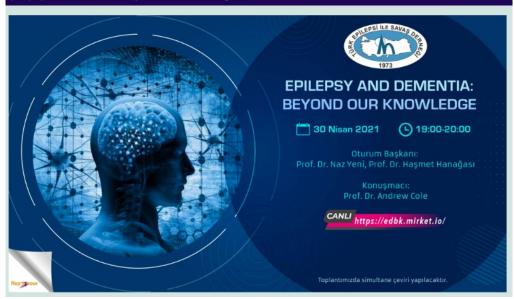


National Epilepsy Congresses were held between 27-30 May 2021, online.



ILAE Chapter Symposia: Prof. Dr. Helen Cross and Prof. Dr. Ömer Hakan Emmez: "Hypotalamic Hamatoma" on 31 March 2022, online.

Epilepsy and Dementia: Beyond Our Knowledge



"Epilepsy-and dementia beyond our knowledge" meeting held online, 30 April 2021.



The Turkish epilepsy journal, Archives of Epilepsy, continued its publications regularly.





#### FDA Safety Warning on the Cardiac Effects of Lamotrigine: An Advisory from the Ad Hoc ILAE/AES Task Force

Co-chairs: Jacqueline A. French<sup>1</sup>, Emilio Perucca<sup>2</sup> ILAE members: Josemir W. Sander<sup>3,4</sup>, Lennart Bergfeldt<sup>5</sup>, Michel Baulac<sup>6</sup> Advisory: David S. Auerbach<sup>7</sup>, Mark Keezer<sup>4,8</sup>, Roland D. Thijs<sup>3,4,9</sup>, Orrin Devinsky<sup>1</sup> American Epilepsy Society (AES) contributors: David G. Vossler<sup>10</sup>, Timothy E. Welty<sup>11</sup>

26 Jan 2021

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FDA Safety Warning on the Cardiac Effects of Lamotrigine: An Advisory from the Ad Hoc ILAE/AES Task Force The paper was sent to our members from the Turkish Epilepsy Society.

Report submitted by Associate Dr. Aylin Bican Demir, Secretary