The Moscow Times
30 YEARS
INDEPENDENT NEWS FROM RUSSIA

Russia Takes on ALS With a Marathon

Watch a marathon to gather funds for Russian patients

By Michele A. Berdy

June 19, 2020



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On Friday the non-governmental organization Zhivi Seichas (Live Now) is holding a 10-hour marathon to gather 2 million rubles for Russian patients with ALS (amyotrophic lateral sclerosis). All day on their YouTube channel or VKontakte page some of Russia's finest athletes, actors, singers, dancers and many others will be working hard to entertain, enlighten, and even hold some dance and exercise classes.

Their goal is to raise funds to help patients with ALS, also called MND (motor neurone disease) or Lou Gehrig's disease (after the U.S. baseball player who died of ALS in 1941). It is a rare disease that destroys the neurons controlling muscle use, although scientists do not yet understand how the disease functions or what causes it to appear. There is no cure and there are now only a few drugs that slow the progression of the disease.

For several years people have been doing the "ice bucket challenge" to raise funds for

research.

I know a lot about ALS because my mother died from it. She was one of the rare people who develop the disease very late in life, and she had the most rare form of it. She couldn't tolerate the one drug that sometimes slows ALS and died about nine months after diagnosis.

What made those months bearable - other than her boundless enjoyment of life and faith - was the help from local aid organizations that provided everything from massage therapy to a vest that helped her breathe.

Zhivi Seichas is the only NGO in Russia that provides help for patients with ALS so that they can continue to live the best possible life as the disease progresses. You can find out more about the organization here.

Tune in to the marathon and consider a donation. No ice bucket required.

Original url:
https://www.themoscowtimes.com/2020/06/19/russia-takes-on-als-with-a-marathon-a70628