

# 2021 STENE PRIZE RUNNER-UP

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*Serbia*



I've got one year to go before I reach 50! I was born in Belgrade where I also graduated from the Faculty of Economics. It's where I live now, together with my family – my spouse and two children. I'm employed. I read a lot, love cooking and making bread. I've become an expert in gluten-free culinary delights due to my younger child having coeliac disease.

Whenever my disease allows me, I do Pilates, qi gong and tai chi. Despite having other diseases alongside arthritis, and often finding life difficult, I am always smiling and optimistic.

I found out about the Edgar Stene Prize competition through the ORS – the Serbian Association of Patients with Rheumatic Diseases. The theme is inspiring in general, but especially so in the time of coronavirus when it's not easy to reach a doctor, and when we're mostly at home uncertain and scared. I wanted to describe my experience which I hope may be interesting to someone. It would be wonderful if it helps give people ideas on how to cope better with disease when you have digital allies at your side.

# 2021 STENE PRIZE - RUNNER-UP ESSAY

## **With a little help from our friends**

Let's be honest with ourselves, we're sick. We suffer from "addiction disorder". We are addicted to digital devices. We cannot imagine a day without them. They enable us to communicate with our friends and to co-operate with our business partners. We use them for research and for study. They entertain us and provide consolation when we're lonely. The Covid-19 pandemic has doubled, maybe even tripled, the time we spend with our digital pets.

We work from home, hold meetings online, write to each other via email and social networks, and nervously scroll through the latest news regarding the virus. Most importantly, we use them to communicate with our loved ones whom we cannot meet and hug due to quarantine, social distancing and the reduced number of times we go out.

Let's be honest with ourselves, we're sick. We suffer from a rheumatic and musculoskeletal disease (RMD). It's with us every day – we wake up with it, go through the day with it, go to bed with it, work with it, grieve and love with it. It annoys us, angers us and scares us, but we carry on living with it and despite it.

Let's ask ourselves whether our addiction disorder can be compatible with our RMD? Can our addiction disorder help us accept our RMD more easily and function more easily with it? This seems to be possible.

One of the first widely-used digital solutions that made life easier for chronic disease patients is the electronic prescription. Even without the pandemic, health centres are always full and waiting at the general practitioner's is inevitable. We turn to the general practitioner for advice on how to maintain and improve our health, for acute illness, regularly or periodically for chronic diseases that include RMDs, to get a prescription for our regular treatment or a referral for a laboratory test, specialist examination or hospital treatment.

Long waits mean less time for the family, more frequent absences from work and an increased possibility of catching an infection in the waiting room. These problems are, at least to some extent, overcome by the arrival of electronic referrals and prescriptions that can be issued for several months, and with the possibility of scheduling examinations and/or check-ups with specialists.

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## 2021 STENE PRIZE - RUNNER-UP ESSAY

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Important and useful information that we've received through social networks during the pandemic has contributed greatly to the practical knowledge and mental calmness of us patients – notifications about the work of the Rheumatology Institute in Belgrade (IRBg), about (the lack of) regular check-ups, about the transition of the IRBg into the Covid system, information on how to receive and deliver our regular therapy. Messages from the Association of Patients with Rheumatic Diseases of the Republic of Serbia (ORS) on social networks and by telephone (Viber groups) has meant a lot on difficult days – days filled with the unknown, fear and loneliness. We had the feeling that someone was thinking of us, that someone cared about us.

Digital platforms enabled the EULAR 2020 Congress, and the Congress of Serbian Rheumatologists and ORS 2020 to be held, which we patients and ORS members were able to attend. We had the opportunity to learn about the newest approaches to RMD treatment, to hear about the experiences of rheumatologists during the pandemic. We had the opportunity to watch exercises that are good and appropriate for our joints and essential to do. At least for a few moments we felt as if we were having physical therapy at the Institute or at a spa, and it was possible to ask questions. All of this meant a lot to us because it's very important to be up to date with your disease, to keep it under control as much as possible, and to find out about new medicines and the development of new treatments for RMDs. All of this was available to us thanks to online platforms.

In the same online way, we celebrated other dates: 2 May – International Ankylosing Spondylitis Day, 10 May – Systemic Lupus Erythematosus Day, and 12 October – World Arthritis Day. During the COVID-19 pandemic, we organised online surveys ourselves and with rheumatologists – all of this is available to patients on the ORS website.

As already mentioned, check-ups with rheumatologist have become less frequent during the pandemic and, several times, have not even take place. The IRBg was – and still remains at the time of writing this essay – in the Covid system. It is not hard to imagine how crowded it will be when the regular check-ups return, when coronavirus departs us – at least in part or, as we all hope, totally. When we patients return again for our check-ups at the IRBg, there will be a lot that we'll have, and want, to tell the rheumatologist. Even without the pandemic, check-ups with the rheumatologist, while regular, are not too frequent and a lot happens in our lives and with our disease between check-ups.

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## 2021 STENE PRIZE - RUNNER-UP ESSAY

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In the limited time that the doctor has for each patient, you need to remember everything that has happened regarding the disease: increased stiffness, swelling or joint pain, depression, side effects of medication and the like. If patients kept a diary of their condition, the picture would certainly be more objective – the experience would be remembered. Diary entries could be compared, which would lead to more a concise presentation of their condition at check-ups. With this in mind, the ORS, together with rheumatologists, pharmacists and IT experts, has developed the mobile phone app MojRA. With the help of this app, important information about the disease course is transmitted to the doctor in a concise and clear manner. MojRA is a breakthrough in the doctor-patient relationship, which would not have been possible without the digital world in which we live.

Disease remission is exceptionally important to us RMD patients and it contributes to our mental stability. When the disease worsens, when even simply going to the shop or doing housework becomes a problem, digital solutions come into play again. If we're employed, we can work online from home. We can learn foreign languages, follow courses and take seminars in so many fields that it would take hours to list everything. All this contributes to mental well-being and feeling – even when everything is so difficult, there is a purpose and meaning to life. Peace of mind is immeasurably important to healthy people, and even more so to the chronically ill.

Let's be honest with ourselves, we're sick. But we have good news. Our addiction disorder may be a friend, ally and helper to our RMDs. It's undeniable that using digital devices and technology helps patients with RMDs in their everyday lives.

So let's grab our mobile phones and laptops, smile and, with much optimism, let's start helping others and ourselves in our everyday struggle with RMDs with the help of the digital wonders offered by modern life.