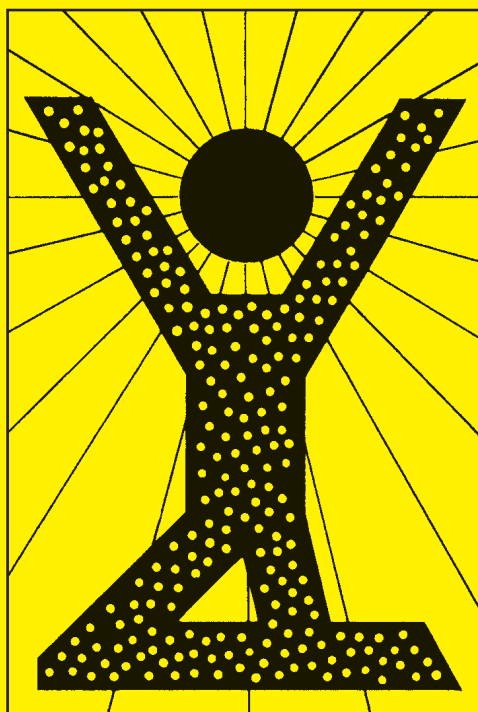


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PSORIASIS



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ŽIVJETI S PSORIJAZOM!

Pisma uvijek donose neku poruku i zato ih treba pažljivo čitati. Dolazi ih mnogo, većinom dobronamjernih, a najviše s nekim željama i sugestijama ili novim idejama. Nije ih uvijek lagano shvatiti jer su često pisana nevještom rukom, ali se kod većine može otkriti ona »zadnja misao«, negdje skrivena kao u zagonetki.

Kad je Psoriasis počeo izlaziti primili smo pismo jednog psorijatičara iz Hrvatskog Zagorja koji se žali da je razina pisane riječi u našem časopisu previsoka te on smatra da mnogi, kao i on, mnogo toga neće shvatiti. U odgovoru podcrtali smo mu dvije stvari. Prvo da od psorijaze oboljevaju ljudi bez razlike na spol, dob, zvanje ili školsku spremu te da prema tome među čitateljima ima doduše i neškolovanih ljudi, ali i mnogo školovanih čak i visoko obrazovanih. Časopis mora svojim sadržajem zadovoljiti sve kategorije bolesnika. Kao drugo bilo je istaknuto u odgovoru da svako prosvjeđivanje mora biti iznad razine onih kojima je namijenjeno jer inače nema svrhe. Ne znamo da li je taj čitalac bio zadovoljan odgovorom. Nije se više javio. Problematiku nasljeđivanja, kod psorijaze tako važnu, namjerno smo provlačili kroz naš časopis i malo ima brojeva u kojima nije dotaknuta. A to je baš bilo ono što je spomenuti čitalac najteže shvaćao!

Nedavno smo opet dobili pismo iz Hrvatskog Zagorja. Jedna majka se zanima za mogućnosti liječenja psorijaze na moru. Njezin sinčić boluje od

psorijaze a u našem časopisu je pročitala toliko lijepog i pohvalnog o heliomarino-terapiji na Velom Lošinju. Na kraju pisma bojažljivo pita da li ima mogućnosti da se kod njezino dvoje zdrave djece odredi gen HLA. Njezin suprug koji vrlo pomno čita Psoriasis ustanovio je da bi to bilo korisno za njihovu djecu.

Mnogo vremena je prošlo od onog prvog pisma. Izgleda da je genetika ipak prodrla u Hrvatsko Zagorje. I ne samo tamo!

Previše ima simbolike u ovih nekoliko redaka da bi ih mogli nazvati samo anegdotom. Oni nas što više navode na razmišljanje o sadašnjem trenutku liječenja psorijaze i o putevima kojima se kreće čitava njezina problematika.

Njemačko društvo psorijatičara je svojedobno na natječaju za svoj simbol izabralo glavu rimskog boga Janusa, glavu s dva lica. To je izvanredno duhovit izbor. No psorijaza nema samo dva lica, ona ima bezbroj lica. Psorijaza je stvarno dermatološka zagonetka. Teško je međutim reći da li je zagonetnija medicinskoj znanosti ili bolesnicima. Obiluje nepoznanicama i čestim iznenađenjima te ne poštuje nikakova pravila igre. Zato je i borba protiv te bolesti teška, bez trajnih efekata i bez sigurne perspektive. Bolesnik mora aktivno sudjelovati u svom liječenju a osnovni uvjet za to je naučiti živjeti s psorijazom. To drugim riječima znači zauzeti stav prema bolesti i dosljedno ga provoditi. Psihološki je to izvanredno važna stvar: biti pripremljen za svaku situaci-

ju. Slično vojniku koji je u svojoj obuci naučio kako se mora ponašati u času napada neprijatelja ili u kakovoj izvanrednoj situaciji. Ako je dobro psihološki pripremljen i znade što mu je činiti neće ga zahvatiti panika. Odnos bolesnika prema bolesti općenito uzevši ima veliki utjecaj na tok bolesti pa i na ishod liječenja. Kod psorijaze je to posebno značajno. Spoznaja da je bolest neizlječiva i još k tome nasljedna nevjerojatno psihološki opteretiti bolesnika. »Osjećaj krivnje« prema potomstvu prati bolesnika čitav život a mnogi zbog toga i ne ulaze u brak. Problema s psorijazom ima mnogo i teško je naučiti živjeti s tom bolešću. Ali to je toliko važno da postaje neophodno. Pogotovo u sadašnjem trenutku kada se još uvijek ne možemo pohvaliti da smo u liječenju psorijaze daleko stigli. Ako je naime suditi po rezultatima, a mislimo da je to jedino ispravno, gotovo bi se moglo reći da posljednjih nekoliko desetljeća u tom pogledu stojimo na mjestu. Istina je da smo mnoge metode tehnički unaprijedili, da su mnogi preparati bolji i za bolesnika sigurniji, čak i nešto više znamo o uzročnim zbivanjima oko psorijaze a genetska istraživanja će u skoroj budućnosti dati odgovore na mnoga otvorena pitanja.

Bolesnik za sada još ne osjeća od svega toga znatniju korist. U većini slučajeva i dalje je upućen sam na sebe, i dalje je prepušten lutanjima kako onim u psihološkom smislu tako i onim stvarnim, tražeći uvijek nešto novo i hvatajući se kao utopljenik za svaku slamku.

Liječniku je isto teško. Najteže je liječiti bolesnika kojem je potrebno mnogo obećavati uz spoznaju da će se malo od tih obećanja ispuniti. Rezultat je nažalost rezignacija. Vrlo često obostrana. I nepovjerenje u cjelokupnu medicinu.

Psihološki stav bolesnika u takovim trenucima ima presudnu ulogu. Znati i moći vjerovati medicinskoj znanosti u trenucima kada je ona nemoćna sastavni je dio onoga što zovemo »naučiti živjeti s psorijazom«. Bez toga nema koegzistencije s tom bolešću a ta je bez svake sumnje nužni preduvjet za dobre odnose na relaciji bolesnik-bolest i osnovni uvjet za uspjeh svake terapije.

Nisu se slučajno i ovaj put s tribine skupštine psorijatičara čuli glasovi koji potvrđuju staru istinu - najvažnije je naučiti i znati živjeti s psorijazom. Bolesnici su to odavno shvatili i sadašnji trenutak psorijaze upućuje ih na to da se toga pravila treba dosljedno pridržavati. Skupština je pokazala još nešto. Očito je da dugogodišnji naponi koje činimo na zdravstvenom prosvjećivanju psorijatičara nisu ostali bez rezultata. Svijest bolesnika se mijenja a s time će se i štošta drugo promijeniti na bolje. Nije samo genetika prodrla među psorijatičare, prodrle su i druge spoznaje i izmijenile način njihova mišljenja i ponašanja. A to je upravo ono što smo zamislili pripremajući davno prvi broj Psoriasisa.

Prim. dr. Daniel Živković

LIVING WITH PSORIASIS

Letters always carry messages and for that reason should be read carefully. Many are arriving, mainly well-meant, most of them with some wishes and suggestions or new ideas. They are not always easy to understand because they are often written unskillfully. In most of them an afterthought may be discovered, hidden somewhere like a riddle.

When the journal Psoriasis started, we received a letter from a psoriasis sufferer from the Hrvatsko Zagorje region who complained about the language being too sophisticated and supposed that many others would not understand much. In the answer we pointed to the two facts. Firstly, psoriasis attacks people without distinction of sex, age, profession and education. Among readers of the journal there are some unschooled indeed, but also many schooled, even highly educated. The contents of the journal should meet expectations of all the categories of sufferers. Secondly, it was emphasised that every enlightenment should be above the level of those it is designed for. Otherwise it has no sense. We do not know whether the reader was satisfied with the answer. The heredity of psoriasis, an extremely important theme for psoriasis, runs intentionally through the journal and there is hardly any issue in which it was not mentioned. And just this was difficult for him to understand!

Recently, we have got a letter from the Hrvatsko Zagorje region again. A mother asks about psoriasis treatment at

the seaside. Her small son suffers from psoriasis and in our journal she read much praise about heliomarinotherapy in Veli Lošinj. At the end of her letter she asks timidly whether it is possible to define the HLA gene in her two healthy children. Her husband, who uses to read Psoriasis very carefully, found out that this would be very useful for them.

Much time has passed since the first letter. Genetics seems to have reached the Hrvatsko Zagorje region. And not this region only!

There is too much symbolics in these few lines but to call them an anecdote. Moreover, they induce consideration of the present situation in psoriasis treatment and the way in which the problems of psoriasis develop.

The German Psoriasis Association invited tenders for their symbol and chose the Roman god Janus having two faces. It is a very imaginative solution. But psoriasis does not have just two faces, it shows numerous faces. Psoriasis is a real dermatological enigma. It is hard to say whether it is a greater enigma for medical science or patients. It abounds in questions and frequent surprises. It does not obey the rules of the game. Therefore the illness is difficult to control and the efforts show no long-time effects and prospects. The patient should participate actively in the treatment and the prerequisite is to learn to live with psoriasis. In other words, this means to take the stand upon the illness and follow it consequently. From the

psychological point of view it is very important to be prepared to face any situation like a soldier who was trained how to behave at the moment of attack or in the state of emergency. He will not panic if psychologically prepared. Patient's attitude towards the illness influences heavily its course and the effect of the treatment. This is very important in psoriasis. The recognition that the illness is incurable and hereditary puts an incredible strain on the patient all his life. Many do not marry for this reason. Psoriasis brings many problems and it is very difficult to live with. But this is so important that it becomes indispensable. Especially today when we cannot boast of advances in psoriasis treatment. Judging by results, and we think that this is the only right thing, we may well say that for few last decades there has been little progress in the treatment. It is true that many methods developed in the technical sense, many drugs became better and safer to apply. We have even learnt more about the possible causes of psoriasis and in the near future genetic investigations will solve many questions now in abeyance.

The patient does not feel any benefit yet. In most cases he should rely on himself. He is left to his own resources drifted by dilemmas in psychological as well as in a very practical sense. He always looks for something new and like a drowning man catches at a straw. It is not easy for the physician either. It is

most difficult to treat a patient who expects promises being aware that any of these promises will be hardly fulfilled. Unfortunately, the result is resignation. Very often on both sides and mistrust in the whole of medicine.

Patient's psychological attitude is crucial in such moments. To know how to and be able to trust medical science at the moments when it proves to be helpless is a part of what we call »learn to live with psoriasis«. Without it there is no coexistence with the illness. It is a prerequisite for good patient-illness relationship and the main condition of the successful treatment.

It was not by chance that from the platform of the Psoriasis Association's Assembly voices were heard which bear out the old truth - it is most important to learn how to live with psoriasis. Psoriasis sufferers have recognised it and the present situation indicates that they should persistently go by this rule. The Assembly showed another thing. The long-standing efforts to educate psoriasis sufferers seem to have produced the desired result. Patients' awareness changes and in this way other things will improve. It was not only genetics which occupied psoriasis sufferers, they were also reached by other cognitions, which changed their way of thinking and behaviour. Just as we conceived preparing the first issue of the journal Psoriasis long time ago.

Dr. Daniel Živković, Editor