

A hand is shown on the right side of the frame, holding a piece of bright yellow fabric. The background is a soft, warm gradient of orange and yellow, with a vertical crease or shadow running down the center. The overall mood is gentle and artistic.

UMETNOST ŽIVLJENJA Z
REVMATIZMOM

fotografije: Manja Zore

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THE ART OF LIVING WITH RHEUMATIC DISEASES

photographs: Manja Zore



Bolnik, 34 let.

Govorica bolečine

// Manja Zore, Jola Škulj

Moje fotografsko srečevanje z govorico bolečine je nastalo kot del obsežnejšega projekta o pojavih revmatizma ter njegovem destruktivnem poseganju v življenja bolnikov na pobudo zdravnika Matije Tomšiča z Inštituta za revmatologijo v Ljubljani. Sporočilnost govorice rok je od nekdanj zaposlovala moje oko in mnoga moja premišljevanja, saj povednost gibov skrivnostno izrisuje neubesedene zgodbe in vznemirljivo zastavlja komajda domljiva vprašanja o ljudeh in njihovih življenjih. Naše roke so poleg obraza najizrazitejši ter najbolj izpostavljeni del človeškega telesa in v njih se prepričljivo zapisuje sebstvo posameznika. Nema govorica izražanja našega telesa in še bolj neslišna sporočila gibov rok presegajo meje sporazumevanj, ki nam jih omogočajo besede, ter sugestivno in natančno pripovedujejo, kako blagodejno nežne ali nadležno težke so poti, po katerih posameznik stopa. Bolne in deformirane roke pa nosijo še drugačno, globlje in presunljivo sporočilo.

Revmatoidni artritis se fizično, s tem pa seveda nujno tudi skozi vizualno podobo, manifestira na zelo agresiven, šokanten in presunljiv način. Deformirane roke je težko prezreti, nemalokrat še težje sprejeti. Ko si soočen s to groteskno podobo, nehote čutiš bolečino tudi sam. Morda je to bolj sočustvovanje kot pa resnična bolečina, kajti nemogoče je vedeti, kako boli, če se sam neposredno ne znajdeš v tej koži. Vsekakor gre za naše neizogibno kognitivno srečevanje z bolečino in prav ta aspekt želi tematizirati moj projekt. Resnično razsežnost bolečine si lahko le predstavljaš in jo v fotografskih beleženjih vizualno interpretiraš. To reprezentacijo bolečine namerno prikažem skozi mehko, toda ali s tem ko se jo trudim ujeti v prizanesljivost lepe fotografije, ne ustvarjam le lepši, prizanesljivejši pogled na trpljenje, ki še vedno ostaja prav to - trpljenje, osupla groza, zbežnost, tudi strah pred bolečino? Mehkoba in lepota sta le namerno uokvirjanje - informacijsko ozadje - tega dokumentarnega beleženja resnice imunsko obolelega, avtodestruktivnega odgovora telesa.

Bolečina je gotovo relativna. Rimljani so rekli, da je bolečina huda le, če je kratkotrajna, če traja dolgo, huda ni. Mnogi bolniki z ekstremno zvitimi rokami - in to je zame resnično presenečenje - pravijo, da jih sedaj ne

boli več, kar se je verjetno mogoče zahvaliti napredku moderne medicine. Tako se skozi fotografski objektiv soočamo tudi z bolečino, ki je ni (več), čeprav njene sledi ostajajo globoko izdobljene v človeško telo, kot dokaz (minulega) trpljenja.

Projekt si zastavlja tudi vprašanje, ali je fizično deformiranje (in s tem huda izguba funkcije rok) nujno tudi psihično pohabljanje? Nekaj bolnikov, ki sem jih spoznala, je bilo naravnost žarečega, predvsem pa odločno nepopustljivega duha. Samozavestno omenjajo, da ne uporabljajo nobenih specializiranih pripomočkov, da se raje potrudijo in s tem krepijo svoje telo. Zame je to ponovni dokaz moči, ki jo imajo naše misli in prepričanja v dialogu s fizičnim telesom.

Poezija bolečine na fotografijah in *avtopoiesis* telesa, ki se srečujeta v tem projektu, naj s to razstavo odpreta temo, ki jo je z umetniškimi jeziki laže razpreti v vsej travmatični kompleksnosti. Moja ključna tema, ki sem si jo z umetniškim projektom zastavljala, je, da bo medicina sposobna narediti bolečino nevidno... Ali pa bo nekje globoko v našem telesu ta danes vidna bolečina ostala očem le manj vidno zapisana in zgolj ne bo estetsko (čutno zaznavno) moteča, tega o kompleksni dejanskosti biosa in o naši človeški kondiciji - ali po Balzacu človeški komediji - nihče ne more z gotovostjo vedeti, še manj pa z zanesljivostjo obetati.

Govorica bolečine posega v hibridnost umetniške in dokumentarne fotografije. Ta hibridnost kot reprezentacijski aspekt umetniškega in dokumentarnega prijema, ujetega v objektiv kamere, je pomenila vznemirljivo pot za delovni izziv. Naj ta *bolečina resnice* v svoj vrtinčasti svet čustev - grozečega in strašljivega - prizanesljivejše popelje tiste, ki se bodo ob teh podobah zaustavili.

The Language of Pain

// Manja Zore, Jola Škulj

Through photography I have experienced the language of pain that developed as part of an extended project concerning rheumatism and the debilitating and destructive effects it has on the lives of its patients, as well as family members. This project has been initiated by dr. Matija Tomšič from the Institute of Rheumatology in Ljubljana. The message of gestures of hands has long been my focus and consideration, due to the explicit body language, which enigmatically draws out the unspoken stories and dramatically exposes the 'just out of reach' issues behind the people and their lives. In addition to our faces, our hands embody the most expressing and most exposed parts of our human self, and have the definite signature of an individual.

The mute language of the expression of our body, and even more so the quiet messages of hand gestures, transgress communication allowed by words; they suggestively and in detail, through gentleness or hardship, tell about the paths along which we walk. However ill and/or deformed, hands carry a much different, deeper, and shattering message.

Rheumatoid arthritis manifests itself physically, and also in parallel visually, in a very aggressive, shocking and heart-stirring manner. Deformed hands are hard not to notice, many times even harder to accept.

When you are confronted with the perplexing image, you feel the pain yourself, whether you wish to or not. This might be more sympathy than real pain, because there is no way of knowing what kind of pain is present, unless you yourself are exposed to it. Indeed it seems to be our unavoidable cognitive encounter with pain - and this very aspect is at the core of my project. The true width of the spectrum of pain can only be imagined and interpreted through photographic memory. I am intentionally depicting this representation of pain through the veils of softness. However, when I try to capture it in the lenience of beautiful photos, am I not creating a nicer, more lenient outlook on the suffering, which still remains exactly that - suffering, astounding horror, daze, and fear of pain? The softness and beauty are just an intentional frame - an informational back-

ground - of this documentary of truth of the body desiccated by immune disease and the autoimmune response.

Pain is surely relative. The Romans have said that pain is really fierce if it is short-term. Many patients with extremely twisted hands - and that to me is surprising - have said that they are no longer in pain, thanks to the progression of modern medicine. So, through the photographic lens, we are confronted with pain that is no longer there, the one which does not exist anymore, even though its memory remains deeply imprinted on the human body, as evidence of past suffering.

The project also poses a question whether physical deformity (and thus loss of hand function) also leads to psychological impairment. Some patients whom I have met have been full of burning determination, real souls not giving up. They confidently mention that they do not use any specialized tools and that they would rather work harder and thus stimulate their bodies. To me that is, again, evidence of the power of human thoughts and resilience in dialogue with the physical body.

Let the *poiesis* of pain in the photos and the *autopoiesis* of the body, which meet in this project, in this exhibit, open the theme that is - in the language of art - easier to comprehend in all its traumatic complexity. My key theme, which I have been addressing with this art project, has been that medicine will be able to make pain 'invisible'... Nevertheless will this pain - less seen to the eyes - remain only hidden somewhere deep in our bodies, and will not be aesthetically bothersome any longer? Regarding the complexity of real *bios* and our human condition - or as Balzac would say *human comedy* - nothing can be said, and even less foreseen, with certainty.

The Language of Pain addresses the hybrid nature of art and documentary photography. This hybridity as an aspect of representation of the art and documentary approach, caught in the camera lens, represented an exciting path for a working challenge. Let this *pain of truth* take those, who pause at the images, to a twisted world of emotions - as terrible and fearful as it may be - and fill them with more understanding and temperance.

Boleča resnica

// Matija Tomšič

Skozi objektiv mlade poklicne fotografinje Manje Zore želimo slovensko javnost in tiste, ki sprejemajo odločitve o možnostih zdravljenja in o razporejanju zdravstvenega denarja, seznaniti s tegobami in vsakodnevnimi težkimi skušnjami ljudi, ki so zboleli za eno od mnogih oblik revmatičnih bolezni. V Sloveniji za revmatizmom zboleva 10% populacije ali v absolutnem številu 200.000 bolnikov. Za oblikami vnetno revmatične bolezni zboli 2-3% ali 40.000 do 60.000 ljudi, od tega za najbolj pogosto in pohabljačo obliko revmatoidnega artritisa 1% odrasle populacije ali približno 16.000 ljudi. Revmatoidni artritis velikokrat prizadene še rosno mlado populacijo. Bolezen trikrat pogosteje prizadene ženske in je žal še vedno neozdravljiva.

Poleg stalnih, trdovratnih bolečin v številnih sklepih, ki so v začetku posledica vnetja in so najhujše ponoči, se sčasoma pojavijo tudi druge vrste bolečin. Po podatkih iz literature po desetih letih od začetka bolezni samo še 50% bolnic in bolnikov z revmatoidnim artritisom lahko opravlja svoje delo. Najpogostejši razlog za to je nepovratno razobličanje predvsem malih sklepov rok. Pogosto gre za prste rok mladih ljudi, ki imajo še vse svoje aktivno življenje pred seboj. Bolečine ob pogledu na razobličene prste so v primerjavi z izgubo funkcije praviloma blage. A ravno posledic slednjega, prizadete funkcije rok, si zdravi ne moremo niti predstavljati: kar naenkrat postane problem odpiranje hišnih vrat, prižiganje električnih stikal ali odstavljanje kave na štedilniku, držanje zobne ščetke, zapenjanje gumbov, da ne naštejemo mnogih veliko bolj intimnih težav. Bolezen bolnico in bolnika dobesedno zaznamuje za vedno.

Nova znanja in nova zdravila tudi bolnikom z revmatoidnim artritisom in drugimi vnetnimi revmatičnimi boleznimi vendarle obetajo in ne nazadnje tudi že kažejo bistveno boljše prihodnost.

Razstava teh fotografij naj laični in drugi strokovni javnosti – pa tudi političnim odločevalcem – vsaj malo bolj neposredno, поблиže predstavi in boleče razkrije breme, ki jo bolnici ali bolniku naloži vnetna revmatična bolezen. V objektiv kamere so ujete težke in nerazrešljive zgodbe rok prizadetih z revmatoidnim in psoriatičnim artritisom ter juvenilnim idiopatskim artritisom v njihovem domačem okolju, da bi lahko v njih razbrali vsakdanje breme, ki ga tem zbolelim zadaja huda in nadležna bolezen. Po drugi strani pa bi želeli v pretanjeno izostrenih zapisih fotografij Manje Zore ohraniti spomin na te bolezni, ki jim v prihodnosti vsi, ki se poklicno spopadamo z njimi, ne bomo več dovolili njihovega razuzdanega in krutega lomastenja po sklepih in duši.

Opus fotografij, ki je pred vami, je tako prikaz neuspešne borbe s temi boleznimi v preteklosti in je svojevrsten dokument sedanosti, ki v sebi enkratno spaja zgodovinsko-medicinski in umetniški projekt. Prepričan sem, da tako izmalicanih sklepov čez dvajset ali trideset let ne bo mogoče več posneti, ker bomo revmatoidni artritis in ostale vnetne revmatične bolezni z odgovornimi medicinskimi prijemi znali, in jih delno že znamo vsak dan bolj obvladati in uspešno zdraviti. Vprašanje je le, ali nam bodo tisti, ki v republiki Sloveniji odločajo o tem in začrtujejo finančno usodo in organizacijo zdravstvenih politik, dopustili, da to svojo smelo ambicijo in premissljeno zavezo do bolnikov tudi uresničimo.

The Painful Truth

// Matija Tomšič

Through the objective lens of the young professional photographer Manja Zore we would like the Slovene public and those who accept decisions concerning treatment and the distribution of health funding, to become acquainted with the hardships and everyday difficult challenges of people sick and ailing from some of the many different types of rheumatic diseases. In Slovenia, 10% of the population acquires rheumatism, which in absolute numbers means 200,000 patients. There are 2-3% ill with inflammatory rheumatic diseases (40,000 – 60,000 people), among them 1% of the adult population (around 16,000 people) suffer from the most prevalent and debilitating type of rheumatoid arthritis. Rheumatoid arthritis is also the most frequent inflammatory rheumatic disease, which many times afflicts even the very young population. The illness afflicts women three times more frequently and is, alas, still incurable.

In addition to constant and persistent pain in many joints (with the worst pain at night), which is in the beginning the consequence of inflammation, the development of other types of pain ensues. Only 50% of patients with rheumatoid arthritis can still function at work ten years after the beginning of the disease (data from literature). The most common reason for this is the irreversible deformity of the small joints of the hands. Many times these are the fingers on hands of young people, who have their most active parts of life still ahead of them. The pain of the visualization of the deformed fingers is quite mild compared to the loss of function. However it is this latter, the impaired function of hands that healthy people cannot comprehend: it becomes harder to open house doors, turn on the lights, take coffee from the stove, hold a toothbrush, button a shirt, not to mention other more intimate problems. The disease really marks the patients, for life.

New knowledge and novel medications give hope and encouragement to patients with rheumatoid arthritis and other inflammatory rheumatic diseases, and also predict better quality of life in the future.

Let the exhibition of these photographs give the public and other professionals – and especially political decision-makers – at least a direct glimpse of the close-up of the painful suffering experienced by the patients with inflammatory rheumatic diseases. The camera lens captures the hard and incurable stories of hands of patients with rheumatoid, psoriatic, and juvenile idiopathic arthritis, in their own home environments, so we can judge their everyday hardships, afflicted upon them by their debilitating, relentless diseases. On the other hand, we wish to preserve the memory of these diseases in the finely tuned photographic records of Manja Zore and we, who work professionally to combat the diseases, wish to eliminate their potential for the widespread suffering and fierce degradation of the joints and souls.

The opus of photographs before you is a representation of an unsuccessful battle against these diseases in the past, and is a unique document of the present, which integrates within itself historically-medical and art aspects of the project. I am certain that we will not be able to photograph such deformed joints in the next twenty or thirty years, because it will become possible (with the help of all of us working together) to treat rheumatoid arthritis and other inflammatory rheumatoid diseases with responsible medical approaches, some of which we already successfully perform today. The only question remains, will the decision makers in the Republic of Slovenia who are planning the financial fate of health care and its policies, allow for our humble ambition and our commitment to our patients to become true.



Bolnica, 33 let



Bolnik, 64 let



Bolnica, 66 let



Bolnica, 66 let



Bolnica, 49 let



Bolnik, 64 let



Bolnica, 66 let



Bolnik, 64 let



Bolnik, 34 let



Bolnica, 33 let

Brala sem o revmatičnih boleznih in o tem, kako se moramo bolniki sprijazniti z bolečino, po drugi strani pa je dejstvo, da me je morala v službo peljati mama ali fant (ker je bilo z bolečimi sklepi pretežko premikati prestavno ročico ali servo volan), postalo zame preprosto nesprejemljivo.

Trenutka, ko bolečina naenkrat izgine, ne pozabiš. Nena-doma lahko skačeš do stropa, vse je peresno lahko, kot da si superčlovek, v resnici pa si ... kot zdrav. Potem šele vidiš, kaj pomeni – biti zdrav.

Ta simptom je neviden in težko ga je opisati. Videti si lahko odlično, a preprosto nimaš energije, da bi npr. opravljaj vsakdanja gospodinjska opravila. Ker je utrujenost težko opredeljiva, lahko ljudje, ki ne poznajo naših težav, mislijo, da smo leni in se samo pritožujemo; nerazumljeni smo lahko tako na delovnem mestu kot doma.

// Dominika,
rojena 1978,
zbolela v starosti 23 let

I have read about rheumatic diseases and about how we patients must become accustomed to pain, however the fact that I cannot drive myself to work (due to not being able to move the steering wheel or transmission because of pain) and must depend on my mother or boyfriend to do it for me, has become unacceptable.

You never forget the moment when pain diminishes, ever! Suddenly you can jump to the ceiling, everything is feather-light, as if you are this super-person, when in fact you have become almost healthy again. Only then you comprehend what it means to be healthy.

This symptom is invisible and hard to describe. You can seem fine to the outside world, when in fact you have no energy at all to do even the most common house work. Because the tiredness can be so undefined, some people (who do not know you) can think you are lazy and complaining; we can be misunderstood in the workplace as well as at home.

// Dominika,
born 1978,
diagnosed when 23 years old

Sledilo je najtežje obdobje. Zamenjal sem šolo, se prepisal na gimnazijo, in to v drugi letnik; novi sošolci, jaz na berglah s hudimi bolečinami, učilnice v tretjem nadstropju, stavba brez dvigala.

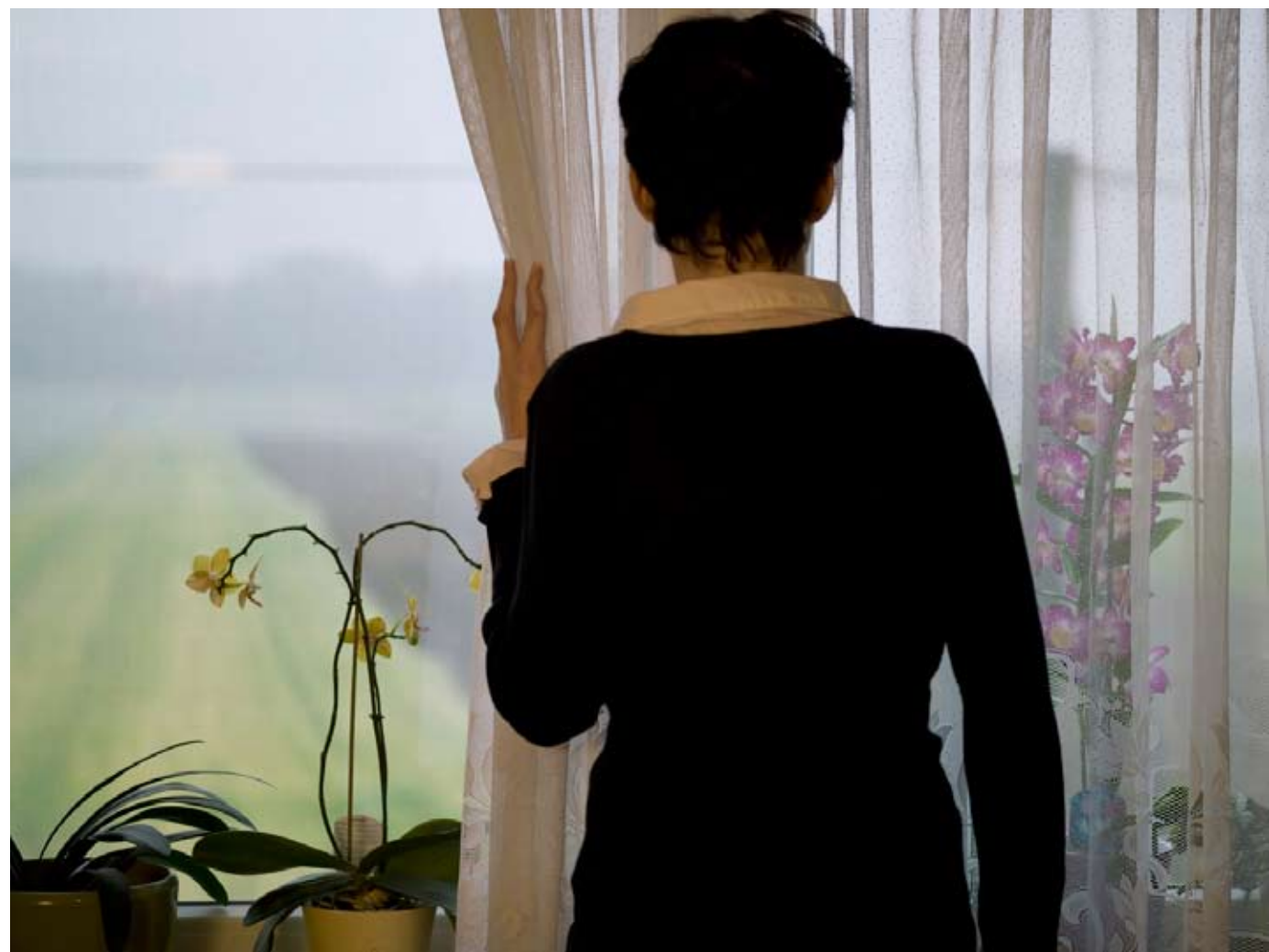
Kako grozen je občutek, ko tvoj otrok pade, kot otroci med igro pogosto padejo, vendar ga ne moreš pobrat, ga dvignit, stisnit k sebi in ga potolažit. In ko ves nasmehjan priteče z razširjenimi rokami in nasmehom naproti, ga namesto z nasmehom in razširjenimi rokami pričakam z bojaznijo, da ne bom padel, da me ne bo preveč zbolelo...ker ima moj sine očeta, ki ga boli že brez dodatnih sunkov, trkov, tudi štiriletnika, tudi sina!

// Ali,
rojen 1974,
zbolel v starosti 2,5 let

What followed was the worst time of my life. I switched schools, transferred to Gimnazija, into the second year; new schoolmates, me with crutches and excruciating pain, classrooms on the third floor, the building with no elevator.

What a horrible feeling, when your child falls (as many children do in playtime), but you cannot pick him up or lift him up, or hug him and give him comfort. When he runs towards you smiling and with open arms, you cannot await him with the same, but rather with fear that you might fall or hurt too much...because my son has a father, who experiences pain without even being touched and with that comes the pain of not being the father that I truly wish to be to my son!

// Ali,
born 1974,
diagnosed when 2,5 years old



Bolnica, 33 let



Bolnica, 33 let



Bolnica, 13 let

» **Manja Zore** se je rodila v Ljubljani leta 1972. Svojo visokošolsko izobrazbo si je pridobila v ZDA, kjer je leta 1995 diplomirala na George Mason University v Virginiji, magistrski študij (smer: fotografija in sorodne umetnosti) pa je uspešno zaključila na School of Visual Arts v New Yorku leta 1998. Deluje kot samostojna ustvarjalka na področju kulture, njene fotografije pa se pojavljajo na naslovnica številnih knjig ter tudi v mnogih revijah in časopisih. Svoje fotografije je predstavila v številnih samostojnih in skupinskih razstavah pri nas in v tujini, njena dela pa so vključena v mnoge stalne zbirke, med drugimi tudi v zbirko Moderne galerije v Ljubljani. Več na www.manjare.com

Pobudnik projekta

» **Izr. prof. dr. Matija Tomšič** se je rodil leta 1959 v Kočevju. Od leta 1987 je kot zdravnik zaposlen na KO za revmatologijo UKC Ljubljana. Od januarja 2002 do junija 2009 je bil predstojnik KO za revmatologijo. Skupaj s še petimi vodstvenimi sodelavci KO za revmatologijo je leta 2009 protestno odstopil z mesta predstojnika.

» **Manja Zore** was born in Ljubljana, Slovenia in 1972. She received her BA degree in Studio Art at George Mason University in Virginia in 1995 and completed her MFA in Photography and Related Media at the School of Visual Arts in New York City in 1998. She has been working as an independent artist in the field of culture since 1999, her photographs appear on numerous book covers, in various magazines, and periodicals. Manja has shown her work in several solo and group exhibitions in Slovenia and abroad. Her photographs are part of the permanent collection of The Museum of Modern Art in Slovenia. More at www.manjare.com.

Initiator of the project

» **Associate professor Dr. Matija Tomšič, PhD**, was born in 1959 in Kočevje. From 1987 onward he has worked as a medical doctor at the Department of Rheumatology, University Medical Centre Ljubljana. He was Head of the Department since January 2002, but due to a dispute he resigned in June 2009, together with five other colleagues who were in charge of different sections within the department.

