

EXPOSE

Igor Koruga

*I want to sing as lovely as Zdravko Čolić
I want to be as rich as Zdravko Čolić
To give to all my fans my pics
To smile at all those sexy chicks
To stay away from politics like Zdravko Čolić*

*I want to comb my hair like Zdravko Čolić
I want to live like Zdravko Čolić
When I was a kid I used to adore
Brena, Boba, Čorba and The Doors
But now it's only Zdravko Čolić*

*They say I'm good and
That my songs
Will be loved by audience
That I must make another hit or two
To build my career very true
Create my image through and through*

*Boy, to your dreams stay true
Your gift is not out of the blue
San Remo is calling you
And another festival or two*

*Crises you simply must endure
Analyses as well, that's for sure
But you have to know
You're a Super Star*

*Musicians, directors, editors, producers
Professors, actors, and other seducers
Everyone says my songs are great
But to be as good as Čola
I'll have to wait*

*I want to sing as lovely as Zdravko Čolić
I want to be as rich as Zdravko Čolić*

ABOUT THE LIFE OF THE ONE WHO IS ONE IN A MILLION

Dear all, to be one in a million is not necessarily something fantastic!

I find it totally pathetic to speak publicly of my health, of my health situation called Primary Immunodeficiency – Primary Immunodeficiency with which I was diagnosed at only 13 months.

And all those comments: ‘It must be painful to bear the burden of the defect!’
Especially as it is painful to bear the burden of any defect,
In particular if it is the defect of the body
Or the defect of immunity which makes your body
Unable to produce antibodies, so your organism cannot fight bacteria and viruses floating around, floating around, they are inevitably floating around!

That is why I need intravenous therapy.
Intravenous therapy is like substitutive therapy.
Substitutive therapy is like invigorating therapy.
And invigorating therapy comes down to one needle, one vein, and a huge KAAAA-
BOOOOOM! And it usually lasts 4 hours.

And I find it inappropriate to talk about the difficulties of it.
And how hard it was to live with it in 1993 when the country could not provide the therapy I receive once a month, once a month, and without which I cannot live.
And how often I get filled with self-pity while explaining over and over again:
What is Primary Immunodeficiency?
And can be healed?
And will I be ill forever?
And am I ill, febrile, hypochondriac or sterile?
And am I ill or with immune disorder?
And what am I taking?
And why can't I receive the therapy abroad?
And why can't I be healed with shark meat, common yarrow, or a long nail on my right-hand pinkie?
And I'm really not into interrupting a moment of intimacy with an explanation why it is so tremendously important to use a condom – not because I can give something to you, but because I mustn't get any kind of disease or bacteria from you... And all those viruses and bacteria that enter my body and leave it, enter and leave, and enter and leave and enter and leave and enter and leave and enter and leave, they leave traces, they leave traces they leave traces they leave traces they leave traces in my body, and turn my body into a sack of bacterial leftovers.

Or to explain how I deal with the calculations the state makes: does it pay off to invest in treatment of rare diseases, and which rare diseases exactly would those be... or if it pays off more to invest in treatment of usual chronic diseases such are asthma, cancer, diabetes, or AIDS.

Or to criticise various pharmaceutical firms and health insurances for hoarding money on account of my health.

Or to keep singing the same old tune of human rights to ever changing clerks from political parties, employed in National Health Insurance Fund – the song of the right to life, right to choice, right to safety.

Or to keep explaining how I've grown up with antibiotics that I've been taking taking taking taking trying to be like everyone else, to be accepted, to be supported, to be loved, to be healthy, to have an attitude, to be in, to be nice, to be critical, to be political, to be charismatic, to be humorous, to be specific, not to be autistic, to be creative, to be progressive, to be flexible, to be open... to be seductive, tender, mature, experienced, courageous, handsome, beautiful, smart, smart, smart, smart...

Right, let's recapitulate that it is not helpful when you say: "Oh, it's nothing serious, I'm just sneezing... let's meet up for a coffee..."

It is also not helpful when doctors in the night shift, barely awake, say: "Primary what...?"

It is also not helpful when an officer in a recruitment centre asks: "Woowh, gee... so you kinda really can't do military service?" "Well, I really can't!" "Well, you're one miserable sod..."

Let's also remind ourselves how unhelpful it is to let mom remain the only source of trust and support – mom the fighter, mom the optimist, mom who believes, mom who encourages, creative mom, mom the illusionary, mom who blows into the needle to make the pain go away, mom who hugs while the fear remains, the comforting mom, mom who reminds you of the therapy, mom who changes therapy bottles, mom who corrects and teaches doctors, mom who understands terminology, know-it-all mom – a Google mom. Mom who is always dignified, mom who always speaks appropriately, mom who doesn't argue, mom who is tolerant, mom who is patient, mom who never cries, mom who endures insults and blows, mom who always understands how other family members feel, mom who sees everything, mom who always finds a cure, mom who makes the non-existent exist, mom who tries to explain that her child's illness is not her fault, mom who awakens and informs the surrounding, mom who stands tall, mom who believes in herself.

Finally, let's summarize how supporting a person with a rare disease with the following words is totally not helpful: "Oh, my gosh, my child, it is amazing how you're handling this whole situation in a mature and responsible way, you're like, really, awesome... awesome!"

For, like: if you want to have your life, you have to surmount the obstacles.

For, like: if you want to make progress, to attain a goal or make your dreams come true, you have to learn how to fight for yourself and how to fight the obstacles in your surroundings, in the government, in the system.

For, like: if you don't fight, you end up in the middle of fucking Serbia, believing that God and not medicine will cure you!

BELGRADE CHRONICLE

Dear viewers, you're watching the show Belgrade Chronicle.

We're facing crisis again this spring. Having been treated by substitutive therapy for years, patients with primary immunodeficiency are once again abolished the financial aid for further treatment. Last year, the patients suffering from rare diseases faced a very similar situation: unavailability of diagnostic tests and centres of expertise, exclusion from health system, lack of experts, medicaments and medical aids, lack of money, administrative obstacles, discrimination... However, the funding necessary for the treatment of those suffering from SECONDARY immunodeficiency – DEVELOPED LATER IN LIFE – are claimed to be AVAILABLE. It shouldn't be forgotten that unless the therapy is regularly administered, any infection contracted by the patients with primary immunodeficiency can lead to sepsis with lethal outcome – and the affected ones are people of the age between 22 and 35. That is our reality.

ADMINISTRATIVE- BUREAUCRATIC LOVE RHETORIC

OFFICIAL LETTER

Department Head for Alergology and Immunology, the Clinical Centre „Bezanijska kosa“ in Belgrade

TO NATIONAL HEALTH INSURANCE FUND, Belgrade

Dear Madams,

I have been informed by the financial director and the chief of Pharmacy of the Clinical Centre that our institution has not been granted the funding from national Health Insurance Fund for next year, for the continued treatment of our 4 patients suffering from primary immunodeficiency. I am therefore forced to send our patients and your insures, to the National Insurance Fund in order to reach the definitive solution to the problem that doctors are not responsible for and in solving of which they cannot participate.

OFFICIAL LETTER

Association of Patients with Primary Immunodeficiency

To National Health Insurance Fund

Dear Sirs/Madams,

As the patients association, we have been informed that the National Health Insurance Fund has not granted the funding for the next year necessary for the treatment of 5 patients. National Health Insurance Fund has responded to our request for the funding, which states that, „all the departments of the National Health Insurance Fund have done what was necessary, save the financial sector“.

As you know, the patients used to receive the prescribed therapy. Our question is: why is this no longer the case and why are our patients put in a disadvantaged position without medical justification. Our question is: Which other criterion has been applied by the state in the exclusion from the health insurance system of our patients whose lives are now threatened without the therapy? Our question is: how important are we to you?

OFFICIAL LETTER

HEALTH CARE CONTRACTING DEPARTMENT

04 Number: 54-569/12 December 06, 2012

CLINICAL HOSPITAL CENTER BEZANIJSKA KOSA

Att.: - Director -

- Department Head for Alergology and Immunology -
No number Bezanijska Kosa Street, Beograd (Belgrade)

RE: Response to the letter of the Clinical Hospital Center Bezanijska Kosa

Regarding your letter, which refers to the provision of additional funds for non-specific immunoglobulins in 4 patients who suffer from primary immunodeficiency, we inform you that the Republican Fund regarding the same matters submitted a response letter, 13 number 54-569 / 12, which we are forwarding once again.

As we too specified in the letter, the Republican Fund determines not, nor specifically transmits funds for immunoglobulin to health facilities/medical institutions. These drugs are funded from the position of the quote/preliminary estimate, "Drugs in a medical institution", the total amount of which is determined for each health facility in accordance with the criteria for contracting health care, which are defined by the General Act of the Republican Fund and within the funds established by the Financial Plan.

A medical institution shall plan procurements itself and it shall be invoicing consumption of all necessary immunoglobulins for the above indication, as well as for all other indications and in accordance with the Regulations on the List of Drugs/Medicaments the mandatory health insurance shall be encumbered with.

Sincerely yours,

RESPONSIBLE BEHAVIOUR

Good evening, welcome NOT to National conference of rare diseases.

Good evening, welcome NOT to marking the International Rare Diseases Day.

- NOT to a panel on the National plan for rare diseases.
- NOR to a roundtable discussion on rare diseases.
- NOT to a rare diseases stand on the Open street fair.
- NOR to one of the popular TV programmes.

Good evening, welcome to *Exposé*: a hybrid theatre performance of public speech and contemporary dance. This is an artwork trying to explore the way in which we use the public space we have left to tackle the questions that are rather not talked about. This is an artwork which explores the ways in which dance comes to exist in the realm of the verbal.

While yet again speaking about the absence of visibility and the absence of justice in our society, I cannot help but wonder: where's the glitch? If I may sum up, our society about rare diseases has not, it has not talked about it out loud. Then we have been flabbergasted to discover that more than half a million citizens of Republic of Serbia suffer from some rare disease. Does it mean that we actually wanted to not notice those invisible people, or is it rather that we waited for, let's say, Sergej Trifunović or Aleksandar Šapić to apply their slender figure, masculine voice, and their capricious attitude, and call us, from TV, to remember our compatriots, to become responsible and to notice and help the... these... those... invisible ones, I mean, the disempowered ones?

On the other hand, we, as a society, are often disempowered by our own state, which ignores its citizens' problems due to its focus on priority issues: should the parliament be dissolved and parliamentary elections called? Does Serbia belong to the EU? What is the status of Kosovo? Is the state capable of fighting corruption? Which criminal groups exist?

However, we, as a society, are inclined to run away and hide behind the excuses that we are disempowered, and to prioritize other problems: we say that this is a poor country; that we work a lot and simply cannot find time for anything; that we have our personal problems to deal with, and that we cannot deal with other people's; that there are more important issues, always some more important issues, and only then turn to something considered rare, and only then solve something considered unknown, and only then solve something that is undeveloped, unidentified, unconventional, not normal, informal, independent, non-governmental, non-state, non-institutional, non-academic, unprofitable, unprofessional,

non-profiled, unorganized, uneducated, non-violent, non-clerical, unpatriotic, non-party, unhealthy, non-gender based, non-common, unequal, powerless, non-family, non-Cyrillic, and non-stereotypical.

And, while we are searching for excuses unintentionally... we randomly find our way around, and then we whine... but we nonetheless confidently claim: **"we act in a responsible manner!"**

We act in a responsible way when we ask an acquaintance "how are you?" and we "don't have time" to hear the answer.

We act in a responsible way when we express solidarity in immediately collecting a million and a half to two million euro to help someone. Not before that someone is about to die, though.

We act in a responsible way when we use social networks to quickly get organized and collect fifteen sacks of our own clothes, footwear, rakia, coffee, honey and milk and send it to asylum seekers from Africa and Asia and then quickly share our own accomplishment on Facebook.

We act in a responsible way when we approve of the fact that the National Health Insurance Fund provides a vehicle to one of their employees to come to Belgrade to specialization every weekend, while, by the way, the "employee" is the daughter of the Governor of the National Bank of Serbia.

We act in a responsible way when we inform the citizens of Serbia that the situation is serious but that there is no need to panic that milk contains alpha-toxin M1, or that the country literally floats on bombs from the First and the Second World War and from the NATO bombardment, but that we should rest assured that teams are constantly in the field deactivating them.

We act in a responsible way when we let our politicians base their political campaigns on hate speech:

that a certain person is the source of evil and should be obliterated;

that certain people are the cause of the white plague and they should remain in the confinement of their homes;

that those dishonourable activists (f), paid by foreign governments have assumed the role of agitprop educators of the society;

that certain nation is “the social, political and moral waste of tribal barbarian Balkans”, which is fighting against “the most democratic, the most civilized, the most enlightened people of the Balkans – the Serbian people”;

that everyone who estranges themselves from pious allegiance to that and that should suffer eternal damnation.

We act in a responsible way when we show no shame that yet another Prime Minister promises that Serbia will come out of the crisis in the next four years.

SPEAKER'S CORNER

Rather than addressing you personally, I'd like to talk to you about a very important fact... which I think all of us are facing these days, months or years...

Let's not beat about the bush, the situation is very clear: The State has capitulated to the citizens!

The state is no longer characterized purely by sluggishness, lack of readiness and lack of organization. The state is now characterized by complete indifference – indifference to its citizens, indifference to any social issues, indifference to human rights, indifference to human existence.

I am well aware that these are some heavy words. But whenever I think of the relationship between the State and these notions (citizens, social issues, and human existence) I cannot help but think of the politisation of those very notions.

I cannot help but think about how the leading political party uses natural disaster and the collective humaneness and the general empathy, as politicized means for reorganizations in the towns governed by the opposition.

I cannot help but think of the state's self-indulgence in the moments of human disaster and of their blaming the citizens of that very disaster.

I cannot help but think of my own fear of the looming scenario I can envisage:

- The state withdrawing from the issue of distribution the society needs: WHO should provide for the flood-stricken and in which way? What about the people struck by something other than floods?
- The state withdrawing from the issues of social injustice, drawing onto the arguments of catastrophe and moralizing regarding the flood-stricken, whereas everyone who belongs to the "others", to the "regular" socially deprived, the counties, the pensioners, the unemployed, etc., will be rejected as a parasite.
- The "social state" withdrawing and turning to the idea by some theoreticians called "participatory society" – in which citizens form their own networks of social care and provide each other with all kinds of things, with ever decreasing help from the state.

And thinking of the attitude the state takes to unresolved issues such as the position of those suffering from rare diseases in Serbia, here is what I can conclude still remains to be solved:

At the moment, **Serbia hasn't got National registers for certain rare diseases; there isn't even a single comprehensive national register for rare diseases, the diagnostics, therapy and process of treatment...** Simply put: it means that if you, sir, in the third row, for example, have a medical problem, and you cannot establish what it is for months or for years... and you have already tried everything: teas, drops, ointments, sports activities, homeopathy, acupuncture, bio energy, standard cardiovascular analyses, abdominal ultrasounds, colonoscopy and other-scopies, and all sorts of micrographs, or allergy tests, tumour-markers... and still nothing.. Well, there you go, you might have a rare disease which keeps getting worse, but what can I say... not a single doctor will even suspect of something like that while conducting various analyses, nor remember it from a university lecture... they've simply slept the lecture through... and it's not like they'll come upon that one case in half a million citizens, i.e. one in six percent of citizens of Serbia.

But in this moment, right now, rest assured! According to a generally accepted definition by the EU – a rare disease is one which afflicts no more than 5 in every 10 000 people... so, relax, calm down... no one but me is ill, you are all safe.

Serbia faces a complete discrepancy between regulations made by National Health Insurance Fund and the needs of the people suffering from rare diseases. That awkward moment when we with PID are asked by the fund: “Why would all that money go to your therapy if your illness... that, primary.. thing... cannot be cured?”

Serbia has a Republic Expert Committee at the Republic Ministry of Health, where doctors make decisions about financing the treatment of rare diseases (the question is whether they do decide anything at all). So, for example, the fund for rare diseases in 2014 is 280 million dinars... After that decision, the committee moved from the Ministry to National Health Insurance Fund, where an instant decision has been reached that this sum should be granted only to the patients suffering from rare metabolic disorders that have been diagnosed this year only... and for the ones diagnosed earlier, well... they have to manage on their own...

Currently, Serbia has the legal framework for rare diseases that is not legally regulated. It means that treatment is based on personal initiative by some medical workers. What it practically means is this – if your child, madam, suffers from primary immunodeficiency, don't worry! There is one single specialist at the Children's Medical Institute in Belgrade. One... a paediatrician. He will take care of your child until it reaches the age of 18, because that is the age until your child, technically speaking, is a child and can, legally speaking, be treated at the Institute.... after that, as some doctors would put it: “It's all in God's hands, madam,”

In Serbia, people suffering from rare diseases are recognised by the social care system only if they have the status of disabled persons. And if many rare diseases are timely treated, the person never acquires that status in its lifetime.

As the “social state” is disappearing, leaving us, its citizens (and people) to our own devices, I wonder: what do we have left? Whom do we have?

I know what you will say: **we have one another!** It has been months now that we are listening about the *spring of solidarity!* And that is, from my point of view, really refreshing, because it seems to me that this solidarity is finally changing its form from “eternal (Yugoslavian) nostalgia” into something else. Into another time. Into another life.

For, all of those humanitarian and other actions in Serbia and the region, all of those the discussions and criticism of the government and the society that we can see on social networks, citizens’ plenums, all of our private-but-actually-public talks in the street – all of that confirms this:

Yes! We can live in the society in which we take care of one another!

We can accept that we, as individuals within a society, have different social and physical skills and abilities. That is why we should talk about our basic needs, without feeling guilty or ashamed. We should collectively try to figure out the way in which we can turn inequalities into justices. We should communicate our basic needs and turn them into social issues/worries.

Yes! We, as individuals, can make ourselves aware that we care about someone’s problem when we realize that that very problem exists in our personal world, among our closest circle of people – in our families, among our friends, colleagues, neighbours. And, if we take a good look at those that we love and care for – THEY lead us towards an understanding that those problems, however rare and unfathomable they might seem, make us leave our cosy nooks and see ourselves through some new structures. Constantly discovering the unknown, i.e. ourselves, we create our responsible behaviour – and not only when we give 50din to a Roma woman in the street...

We, as individuals, can, at least temporarily, dispose of our daily social roles of “extreme nationalists and football supporters”, “righteous leftists”, corrupt doctors”, “patriarchal bullies”, “elitist academics”, idle artists”, “scabby gypsies”, “dressed-up gold-diggers”, “sissy faggots”, “boring anarchists”, “voluble pensioners”, “neutral majority”, etc., and come up on stage of the community in a sympathetic, self-organized, different, united and strong fashion!

Let me sum up: we can do all of that! Let me ask: what do we do with that?

Shall we, a couple of weeks or months after natural disaster or social crisis, go back to ordinary social roles we usually play to one another and for one another, or shall we, after the solidarity we have displayed trying to deal with the consequences of the state negligence, pose the question of the responsibility of all of those who have brought us in this present position?

Shall we continue dividing ourselves into the first-rate and second-rate citizens, and non-rate citizens?

Shall we, as a society, overcome the temptation to drown in the sea of self-congratulation for the revived solidarity or shall we ponder if the state can and should rely on our solidarity only?

What do you think about during every new rain or storm?

Do you expect something from the next Monday?

I expect us to still talk about these subjects. Thank you very much!

EPILOGUE

Now, c'mon Maniac, let's get into party-crowd.

We're dancing ants-like

Brandy's flashing, chicks are around!