

FACE TO FACE

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Love

BELIEVE

FAITH

HOPE



Viktor Dimitrijoski and Bubo Karov
"Pancakes? No, thank you"

By his appearance and interests Viktor is no different from his peers, but he is different in something else. In his life he has never tasted chocolate, pancakes, ice-cream, walnuts, eggs, soy, meat or white bread. Since he was born he is on a special diet which is extremely expensive. The inability of his organism to process the intake of proteins in the usual way renders him nervous, angry, aggressive and scared of places with too many people and in advanced stages the disease phenylketonuria can bring to physical and mental disability.



Iva Petrevska and Dani Dimitrovska
"A bell in a bubble"

A gentle touch, pressure, tiny injury or scratch is a threat to Iva's skin, as gentle as a bubble. The slightest daily childhood activities are the reason for painful sores on her body that require constant care and dressing; and very often the mucosa of internal organs is affected.

Presently there is no official therapy for epidermolysis bullosa

FACETOFACE

"A rare day to put
rare diseases
in the spotlight!"



Rare Disease Day

**RARE
DISEASE
DAY**



When?

The last day of February every year

What?

Rare Disease Day is to raise awareness for rare diseases and their impact on the lives of patients and families.

Where?

Thousands of events around the world! EURORDIS organises the international campaign and National Alliances and other rare disease patient organisations hold events locally.

> Visit rarediseaseday.org and find an event near you!

Who?

For everyone!

The Rare Disease Day campaign targets the general public and policy makers and anyone is welcome to join: patients and their families, patient organisations, health professionals, researchers, drug developers, public health authorities - the more, the better!

How?

Since Rare Disease Day was created by EURORDIS in 2008, thousands of awareness-raising activities have taken place throughout the world reaching hundreds of thousands of people and generating local and international media attention.

We hope many more will continue to join us!

rarediseaseday.org



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FACE TO FACE

Lack of institutional as well as human support



Klimentina Ilijevski

The making of this edition of Face to Face was nothing like before. We had a heavy burden on our shoulders to deal with and in short, it was like a blow to our face, a wake-up call. We had the privilege to be around rare people who are feeling forgotten and neglected for ages. You can see in their eyes that they are happy because you understand them. That's it. You get them.

The making of this show was a lesson for us-series of confessions which are a picture of the system and the society, picture about the drama that these people live through day after day. It is due to the situation in general, the lack of diagnosis, the lack of medicines, and the exorbitant sums needed for treatment that these people turn into smugglers so as to survive. It is because of all of us.

First comes the dealing with the feelings of helplessness due to the illness and the challenges it carries with it, especially in the countries which do not have a solid system for treatment and support of these people. Here also is the feeling that you are alone in your battle. Your problem is your own and it only alters the life of those around you. As an odd one you are faced with exclusion.

Some of the people with rare forms of diseases are left out of the education system and do not get the necessary services for improvement of their quality of life. Others, where the illness has left no physical evidence, hide their illness due to fear that they will be fired.

Recently, in a talk show the journalist asked his guest speaker, a patient with rare disease, if you were not so astute, where would you be today? The answer is devastating – in an invalid chair with only five more years to live. Azemina (the girl who is on the cover on this edition) crossed the gap between life and death. She is the first patient diagnosed with Gaucher's disease which managed to obtain a refund from the state for her therapy within the frameworks of the program for rare diseases which costs more than 100.000 euros on annual level. That was the first change championed by this program where only patients diagnosed with MPS 2 Hunter syndrome had obtained therapy until then. This was the point where the efforts of Life with Challenges took off for forming an alliance with the other organizations for rare diseases.

However, there are still families that continuously struggle to secure 5.000 to 300.000 euros for annual therapy of different forms of rare diseases while the state does not refund them the means later.

Through the exhibition Hug The Odd One! (whose photographs are included in this edition of the magazine), we demonstrate the challenges through which the people with rare diseases go through and the cover which is part of the same exhibition is a confirmation of a wanted outcome of a story. Unfortunately, this is not a common story. We also illustrate the effect of the advantages of perhaps not the simple, but clear and powerful demands of these patients – timely diagnosis and an appropriate therapy and support from all of us. The moving force is in the citizens and they make the change with the pressure for changes which alerts the institutions.

It is because of this that Azemina today is not different from her age group. She is quiet and shy, like all the girls of her age, but sparks of life and love shine in her eyes. That is a true celebration of life that can be seen in the look of every child. Her parents are forever grateful to all the people who were part of different commissions and who raised their hand in order to make what is the only logical and humane thing. “Tamara” the outcry by the people on the streets is an honest human outcry, a cry stemming from heartache, an expression of revolt against the institutions, the system and the poor decisions of the commissions. Above all, it is a cry for revival of the basic human values.

It is an outcry for turning the death into a dignified life.

FACE TO FACE WITH MIROSLAV DAVIDOVSKI

DON QUIXOTE WHO DEFIES THE WINDMILLS OF LIFE

Maja Nedelkovska



Former ballet dancer and bohemian, a man who enjoyed his profession and life, he became an alcoholic since he couldn't come to terms with the tragedy which besieged him. Now, however, he is an active OAP and proud street vendor of "Face to face"

Cheerful, with energy and spirit suited to a young lad, with readiness to help anyone and give advice where necessary. That is the first impression after a conversation spent with one of the newest vendors of our street magazine, Miroslav Davidovski. Such are all the following impressions. Miro, as he is known is just like that, polite, well mannered, attentive and fun. He regularly cheers everyone with his jokes which are very often on his own account. He joined the team of vendors of "Face to Face" as a person who has faced the problems that

alcoholism brings and comes from the Association of Clubs of treated Alcoholics of Republic of Macedonia, the only one from there who understood the mission of a street magazine "at first". He has enough stories for five lives, from each period of his life up to now. A former ballet dancer and a bohemian, a person who has enjoyed his profession and life, he became an alcoholic since he couldn't cope with the tragedy which besieged him. Now, he is an active OAP and a proud vendor of "Face to Face". We start his story from the beginning.

A NAUGHTY CHILD WHO GREW UP IN THE THEATRE

He grew up as a child of the theatre and he built his professional career in the Macedonian National Theatre as a soloist in the Ballet.

-I was born in the most beautiful neighbourhood in Skopje in Debar Maalo. My mother worked in the old theatre and after school I would usually go there to the place reserved for me – the second balcony. I had seen all the plays and I remember everything. For me it was a real magic – tells Miro and adds that one of his favourites was "The Chimneysweeper Sam", the first opera for children, which he remembers well, as well as "The Land of the Smiles"

As a third and youngest child in the Davidovski family he was very naughty, so his sister had enrolled him in the primary ballet school which proved to be his destiny.

-And so I followed the steps of Terpsichore, the muse of the dance and choir singing. Since my beginnings, at the age of 12, I also participated in TV shows "Our Crossword" and "Chavka Slavka". I had been earning royalties since I was a child; I had known how to earn money since I was very young- smiles Miro.

LIFE AS A BALLET ARTIST

Today he does not miss one premiere of the Ballet and the Opera and says for his wife and he there are compulsory two tickets. He recalls that he started to do professional ballet shows with greater intensity and dropped out of the studies in South-Slavic



Literature, and, as he says, was employed as a soloist with the ballet within MNT.

-After an article in "Vechernje Novosti", where they praised our dance (with Zorica Purovska), I started receiving offers from many theatres of former Yugoslavia. I decided for Mariborsko Gledalishche, where I stayed for 6 months and through that cooperation I went on to work in Gratz- recalls Miro.

He says that although he lived like a bohemian with many friends he did not feel as a star, but he knew how to enjoy every moment. After these engagements what followed was the serving of the military service- he was a trumpeter in the army in Kraljevo and in Belgrade. The years of his professional career in MNT, that is in the ballet had brought him many premiers, friendships and beautiful moments. He performed head to head with the renowned Olga Mirosavljeva, Zorica Purovska, Marija Kichevska, Irena Veterova, Tanja Vujsik-Todorovska as well as Aleksandra Mijalkova, Katerina Kiprovskaja and many others. Some of his favourite roles are "The dance of the caddettes", "Swan Lake", "Bahcesaray's fountain", "Don Quixote".

-My professional life is like a painter's ladder. I had started climbing up since I was a child, and when I had reached the zenith of my career, there was little else but to start coming down from it- he says.

He retired in 2002.

-I did not have one hour of sick leave or leave of absence from

work- smiles Miro.

In the days of his retirement he did not wish to remain outside of his profession, but he turned towards educating the youth and together with few other artists and pedagogues they have established the Cultural and Education Centre "Scene". This highly professional studio educated children and youth. -I did not wish to make them only ballet dancers, but to educate them and to develop their sense of hearing and rhythm, posture. I had a need, simply, to transfer my knowledge- he says.

FAMILY TRAGEDY HAD BROUGHT HIM INTO ALCOHOLISM

He describes himself as modest, humanist, blood donor and solidarity person. Truly, Miro is such. Without taboos he openly talks about his great vice- the alcohol. He says that he does not look for excuses, but that was something that he simply could not control.

-In 2004 I suffered a great tragedy. That year I lost my closest family, everybody died- my mother, my father, my sister, my brother. I could not deal with that. It was then when my troubles with alcohol began. I knew that I was going into the deep and that I needed treatment that I was dealing a serious illness- recounts Miro. He has been treated for many years and hopes that he will succeed in this field as well. He is very pleased that his wife and two daughters showed strong support and he is very proud of them. Miro is also an active OAP:

-With the association of OAPs we travel around the country and abroad, we socialize and it's nice. I want to discover new things, places and people, I do not have problems whatsoever establishing communication. Perhaps it is that desire for new things has led him in his days of retirement to be a successful vendor of the only street magazine in the country. His favourite area is Aerodrom and you can encounter him at Bunjakovec and Debar Maalo, very often you can meet him with his colleagues at MOB. Stop him by, he has plenty to tell.

“FACE TO FACE” TOPIC

AWAITING SYSTEM CHANGES AND
SUPPORT FOR RARE DISEASE TREATMENT

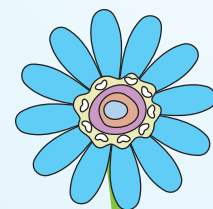
Battle to the end of life

Aneta Risteska

A rare disease is a complex state. Sometimes, it encompasses a group of several illnesses that attack the organism. Part of them are treated, for some there is not a cure, and for others the price that needs to be paid in absence of support is too high, credits, debts, trafficking of expensive medicines...

What future awaits my child? This question resonates for a long time through the head after you read or hear the stories of parents of children suffering from a rare disease and who face many challenges throughout life; the overcoming of which demands an out-of-this-world strength, especially if the environment around you is not your ally, but your enemy or just a mute observer. One would say a rare disease an even rarely given hand. But the stories of Iva, Ana-Marija, Viktor, Kiki, Dejan, Andrej, Maksim, Markijan, Marta, Viktorija, Azemina are proof of the incredible energy that humans carry within and with themselves especially when facing the challenges which living with a rare disease brings along. They are all part of a hard to define number of patients in Macedonia who need support in order to have one of the basic human rights, the right of health, health protection and better quality of living. Although Macedonia does not yet have an official registry

of patients who suffer from a rare disease, still the Association “Life with Challenges, which most actively works on defending the rights of these people, points to the fact that in the country there are at least 200 people suffering from a rare disease and they have not received treatment remunerated by the state so far. But if we follow the definition of the European Union that a rare disease is a disease that occurs with one person in 2000 then the assumption is that more than 1000 citizens in our country are facing a rare disease. Unfortunately, their journeys though the labyrinth of life that these diseases carry, of which some are still unnamed, show that our fellow citizens sometimes find the real exit with excruciating difficulty. The search for a second chance lacks not only system support but also human, citizen support. The suitable recognition, classification and codification, insufficient access to diagnosis, limited therapeutical possibilities, unequal and insufficient quality of health care, high price of treatment and care, serious consequences, isolation and marginalization of the affected are briefly the main and major challenges that every community and state faces in the approach to and dealing with rare diseases. But the endeavours that result with positive changes in this segment of health care are also the main difference among



separate countries in Europe and in the world.

What are the steps in our country in order to improve the quality of life of people with rare diseases? How and when their treatment is aided? How far is the preparation of the registry of rare diseases and patients suffering from them? Does the budget foreseen by the Health Fund cover for the needs of treatment of all patients? What is their life like, how easy or hard do they arrive to their workplace, but also how much are they marked by the environment? Whether our country has enough trained medical staff to set an early diagnosis for a rare disease? Who pays for the analysis abroad? Is there remuneration of funds? How many Macedonian students of medicine encounter literature on rare diseases in the course of their studies? Does Macedonia invest in research on rare diseases?

Unfortunately the answers to these and many other questions are for now rare or incomplete. Is that a result of the fact that in Macedonia the conversation on rare diseases started only in 2009 or everything here is subjected to marginalization when rarity is in question?

Nevertheless, one is clear that rare diseases should not be talked about, written about or heard of only at the end of February when the International Day on Rare Diseases is marked, but throughout the year, because these people strongly embrace every new day and besides the rare disease they have a rarely strong will and desire to live longer, better and with greater quality.

LEFT TO ONE'S OWN MEANS

Ana- Marija Vlastimirova is 13 years old and is the first registered patient in Macedonia suffering from RETT syndrome. The symptoms of this disease in most cases occur in the second year of life. It has four stages each worse than the previous. It is manifested with epilepsy, cerebral palsy, scoliosis, allergy to gluten and casein, mental retardation and disruption of the metabolism. If the patient ever walks then the walk is apraxic which ends in immobility. The last phase when death is expected according to some findings, most often happens in sleep.

From the talk we had with Ana-Marija's mother, Biljana, we found out that alongside her daughter there might be 2 other cases suffering from RETT syndrome in Macedonia, in Ohrid and in Delchevo. However the non-

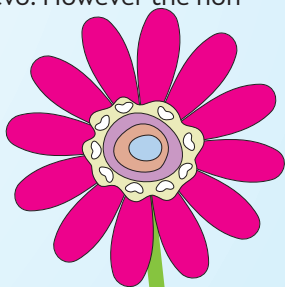
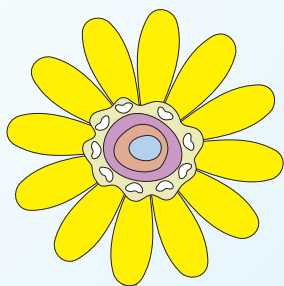
existence of an official registry disqualifies these claims. She says that when they first found out about the disease, especially because they were the first case in Macedonia with RETT syndrome, they did not receive any greater help from the doctors. The help came from abroad.

-We received support from the doctors from Belgrade. Their selflessness helped us to persevere. The therapy for Ana-Maria is comprised of four parts of which none is a medicine, only a supplement. Physical therapy, gluten-free and casein-free diet, defectological and logopedic exercises and socialization and supplements for all the enzymes and aminoacids that her organism needs- explains Biljana Vlastimirova.

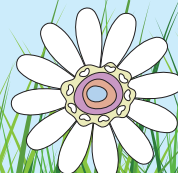
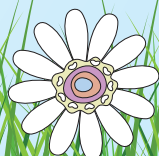
Part of the necessary supplements are provided from abroad and part in Macedonia, but in this part they do not feel any help on the part of the state. We are simply left to ourselves.

-We have no support whatsoever from the institutions in this part. For now the Health Insurance Fund has only allowed for gluten-free flour. But what are we to do with the flour alone? We need full range of gluten-free food. It only takes one word in the Rulebook to be changed, "food" instead of "flour". From the Ministry of Health they were to assign us a physical therapist and from the Ministry of labour and Social policy – defectologist who will work in domestic conditions. This was never provided and those who have money they pay for this, those who don't – rob the child of these therapies – says Ana-Marija's mother.

The strife does not end here. As Ana-Marija grows, so do the number of problems the family faces because a rare disease does not mean a struggle of a single person but of a family as a whole.



9



According to the statements of parents that have a child with a rare disease, but also of adult patients, neither the state nor its citizens have an acceptable level of awareness for these fellow citizens.

Almost all affected share the feeling of discrimination, marginalization, isolation and helplessness, the feeling as if they are not part of society.

- The truth is that these people are not really accepted by the environment. We are witnesses of situations of everyday stares from passers by who are usually frightened by the sight. Here these children are completely excluded from the educational process, what else is left to be said –says Vlastimirova, who is also a president of the Association “Kokichinja” and a contact person for the European Foundation for RETT for Macedonia.

Joining with people who have the same or similar problems very often, at least to some extent, alleviates the struggle with the challenges this patents face. The exchange of experiences, advices, information makes them feel that they are not alone and that perhaps the next contact will bring news for a new medicine, new possibility for a better quality of life.

-Alongside the regular attendance at the seminars in Belgrade at the Institute “Mother and child” the talk with the parets helps me a

lot in facing everyday problems. I am also connected to the interational network Internatioal RETT Foundation on the internet and there all the parents communicate with each other – adds Ana-Marija’s mother. The education of doctors, the feeling and understanding of our needs and demands, information on the newest research in the world about any rare disease, available medicines are only a part of her recommendations because, as she says, this is the only way to make life bearable for these people. -It is necessary to give us hope- ends Biljana.

CREDITS, DEBTS, SMUGGLING OF EXPENSIVE DRUGS...

The case with Ana-Marija is only and illustration of part of the problems people suffering from a rare disease face in Macedonia which unfortunately does not yet have accurate data about how many patients with rare disease live on its territory.

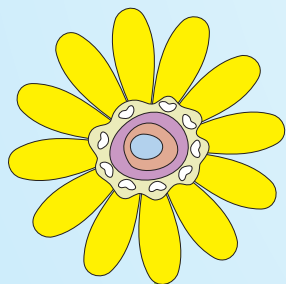
A rare disease is a complex situation. It sometimes means a group of several diseases that attack the organism. Some of them are treated, for others ther is no cure, and for some the price that needs to be paid, in absence of support, is too high. Credits, debts, smuggling of expensive drugs; these are only few of the means people suffering a rare disease have to undertake either directly or through family members. Unfortunately, there is no register of rare disease medicines that can be obtained in the country , and some of the families fight the struggle to provide from 5000 to 300 000 euros for an annual therapy for a

particular disease, money which are not remunerated by the state.

-The medicines and equipment for rare diseases are of humongous importance. For example, a child with muscular dystrophy, who has problems with breathing, is necessary to have machines at home. The same is for wheelcharirs. Only, for rare diseases they are not on the positive list. They simply are not entitled to. The greater part of the medicines are with incredibly high prices and a good part of them are new and not available on our market. Thus, the medicine we use for our son Markijan(suffering from tuberous sclerosis, a disease which occurs once in 6000 children) was invented five years ago and despite all our endeavours it has not yet been put on the positive list. We have been brought to act as traffickers only to get to a certain medicine- says the pop-singer Rebeka, president of the citizen association for people with disfunctions, handicap, rare diseases and with special needs “Dajte ni Krilja”

For “Face to Face” she opens the issue of inclusion of children with rare disease in all social courses. She says that prejudices which our society generally has towards people with rare disease whose rights are not regulated by law are not yet gone.

-Inclusion in the education, even from the earliest stages, is still a taboo with us. There is a complete lack of interest for integration of these children in society. Simply there is no feeling of the gains that these children would have if the doors to regular education were open to them, and we all know how much inclusion improves their cognitive development, communicative abilities because they learn from the other children in this way.



Also attention must be paid to the education of teachers- adds Rebeka.

Not enough experience, not enough information, education and training of Macedonian doctors, the bad and/or belated diagnosis, incomplete analysis and skipping important check-ups, as well as therapy with wrong medicines, are only few of the problems that the patients suffering from a rare disease in Macedonia point out.

Sometimes the doctors do not have an answer for an occurrence, it is bad that they do not have decency to say that they do not know to admit that and they play "godfathers" to the diseases baptizing them only after the symptoms, but there is no diagnosis. This, above all is due to the absence of necessary tests in the country and the inability of parents to pay for diagnosis outside the state because the diagnosis is not covered neither by the Health Insurance Fund nor by the Ministry. Thus there are situations when, for example, parents, forcibly, become more informed on the disease than the doctors themselves- say people who directly or indirectly pass

AWAKING HUMANITY

What is the awareness of the Macedonian citizen when rare diseases are in question and whether its support qualifies as self-initiative or is it manifested as joining initiatives that have already started?

The president of Life with Challenges answers this question and says that if some events are left out, Macedonia is still a country where the citizens respect each other and are very humane people

-As an association we have received the support of many private companies and state institutions, but also from individual citizens who simply want to support us in our struggle for our rights as patients with rare diseases. It is because of this support that we have managed to achieve certain changes in the treatment of the rare disease and we plan to continue working led by the needs of the patients and their families- she says.

The support itself can be seen in the fact that two years in a row more than 100 people join the Skopje Marathon in the Group "Running for better Life", and around 50 people have joined the climbing of Korab- the highest mountain top in Macedonia, two years in a row as well.

These are activities for raising public awareness. We believe that they are always necessary and not only for raising the public awareness of the wider public and institutions, but also to the families and patients themselves because in this way they more patients each year are encouraged to tell their story and and to publicly talk about their problems and needs. Our honorary members are Mary-Jo Wallers (wife of the former US Ambassador in Macedonia) and Maja Ivanova the First Lady of Republic of Macedonia- adds Aleksovska.

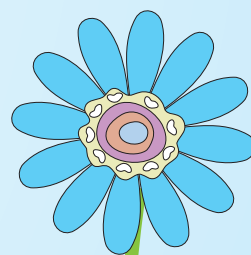
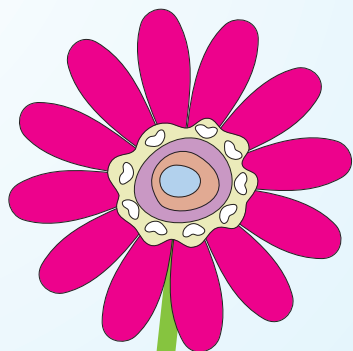
through the labyrinths of the disease.

All praise, they add, goes to the doctors who are fully devoted to their profession who are conscientious, humane and dedicated to their professional life choice, who step out to meet our needs when possible. A good part of them use the cooperation they have developed with colleagues from abroad in order to provide additional information and support for the patients in Macedonia.

Unfortunately, the battle for a more decent life still is being fought by the people with rare disease themselves and their families, sometimes encouraged at others fallen, but always with the hope that the community's awareness will have an important awakening which would later

implicate activities which will result in essential system changes and improvements for them.

In such situation of "loneliness" very often the social networks present themselves as a window to looking for an exit from the



difficult situation in which people with rare disease find themselves. Thus a part of them more often than not manage to reach the opportunity for treatment of their condition through donations from foreign companies and foundations rather than from home. Yet, all rare diseases need life-long treatment. Battle to the end of days!

TREATMENT BASED ON DONATIONS

Receiving valid and timely diagnosis is also a true rarity. Some of the researches show that patients, on average, wait one to seven years to get the real diagnosis and that only adds for the illness to progress with what all the symptoms become more aggressive. These difficult paths to identifying the real disease are long and cumbersome and the whole condition is additionally aggravated by the fact that many of the existing therapies and medicines are expensive and are not on the positive list.

"We do not want to be invisible people" state the people with rare diseases in Macedonia and they engender hope for a more decent life through the renewed functioning of the Commission for rare diseases which since it was formed in 2009 it had a long break in its working, only to put in its focus again the problems of rare disease patients. Its chairperson Aspazija Sofijava, who at the same time is the managing director of the Children's clinic, where patients with rare disease receive the first support and life-long observation, claims that for a certain group of rare disease

ADOPTION OF THE STRATEGY AND ACTION PLAN FOR RARE DISEASE IS DEMANDED

What is the approach to solving the problems related to rare diseases in Europe and in the world, in general? Can we make a comparison?

These are questions which undeniably pose themselves when rare diseases are the issue and the information say that each country has a different approach.

The European Union understands the challenge of rare diseases and six years ago it has adopted recommendations on how to face it. Further on, throughout the years more recommendations were created for different aspects of life with a rare disease, but also recommendations and initiatives to increase the research for medicines in the area of rare diseases.

The President of Life with Challenges especially emphasizes the importance of the recommendations for creating a strategy for rare diseases, that is, creating an action plan to face the challenges.

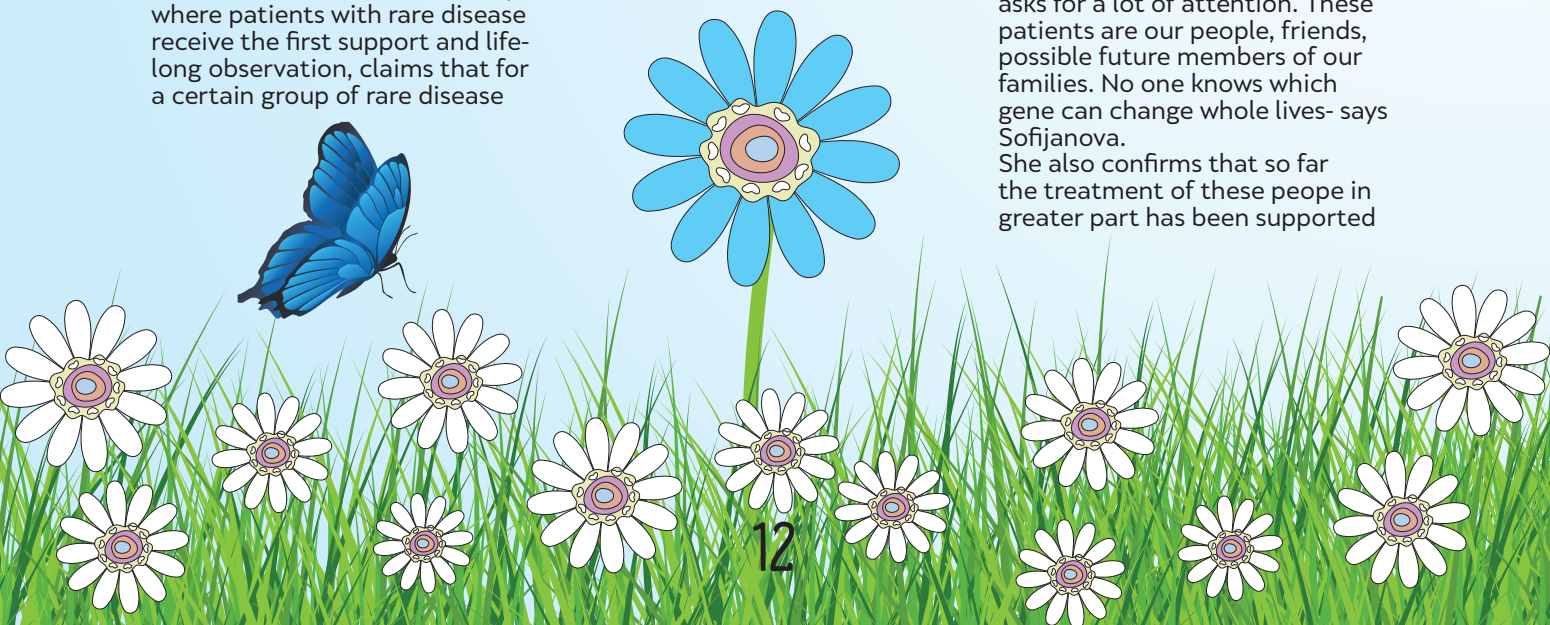
-Such strategic plans include more aspects such as diagnosis, register, prevention, scanning, education, cooperation, exchange of experiences and expertise, research, specialized health and social services etc. I will not go very far, it is enough to mention our neighbours regarding plans. In Bulgaria a second rare disease strategy is already being implemented, in Bosnia and Herzegovina the strategy was adopted last year and in Serbia it is being adopted this year as well as in Croatia; in Montenegro it has already been adopted and is being implemented. In Macedonia as a National Alliance for Rare Diseases we have created a proposition- strategy for rare diseases and we hope that in near future it will be reviewed by the Ministry of Health and of course put to public discussion in order to improve it and further adopt, to be suitably implemented through an action plan which will encompass all the relevant institutions, organizations and health institutions- explains Aleksovska.

there is the possibility for early diagnosis, but for most of them diagnosis is reached only through collaborative laboratories from foreign countries.

-We are as small country and are in a phase of accreditation of laboratories in the framework of which there will be molecular and cytogenetic laboratory for diagnostic, because the factors that complete the overall clinical

and genetic diagnostic are very particular. I think that we are consolidating in this segment and that we are coming closer to the EU, although we have many steps to pass and climb. However, the endeavour for treatment and improving the quality of life of these persons is definitely and undeniably increasing. Let us not forget that the life of these people is full of challenges and asks for a lot of attention. These patients are our people, friends, possible future members of our families. No one knows which gene can change whole lives- says Sofijanova.

She also confirms that so far the treatment of these people in greater part has been supported



by donations which are not always available to everyone, but adds that from now the state through the Rare Disease Programme within the Ministry of Health will make endeavours to provide treatment and medicines for all people suffering a rare disease. Science can also give many answers related to rare diseases. Researches very often network in order to exchange results from their researches and open new perspectives. The last 10-15 years an overall progress can be felt in terms of diagnosis and treatment of rare diseases but this development is not equal everywhere.

MANU (Macedonian Academy of Sciences and Arts) three years in a row organizes a Congress on rare diseases, hoping that there will be advance in the field of treatment and patient care.

-Rare diseases mark the 21 century. Researches are carried out in MANU, but only as much as the conditions allow, with very

LABYRINTH OF PROCEDURES, FEARS, QUESTIONS...

"As parents we share our compassion with all the parents whom life has posed such a trap, their eyes to see and their soul burn while their hands and feet are tied and they are powerless to help their children..."

This is how Aco and Verche Dodovski, parents of twins who were diagnosed with juvenile rheumatoid arthritis at 12 and 19 months, begin their story for the past years when they first faced the rare disease diagnosis of their children.

They themselves do not know what was more difficult for them, whether it was the time when they wandered from doctor to doctor looking for information what happens to their child (the symptoms first occurred with one of the twins, and when the other one had the same symptoms the diagnosis was already in place) or the period after the diagnosis and facing the fact that not only they will face long-term symptoms and consequences of the disease, but also the problems that unavoidably occurred due to the inability to follow, control and treatment within our country.

-The moment when they had to receive therapy unknown to us personally, and to our environment as well and because of control of the overall condition it was necessary to have a constant surveillance from a doctor, it happened so that we lost ourselves in the labyrinth of numerous procedures administrative and of every other kind; not-registered medicine and lack of experience with this kind of therapy, which has led us in a more difficult situation – a need to provide the medicine from abroad, fear of administering the therapy and possibility of side effects, but also the thought: Who will intervene in case of side effects? – recounts the Dodovski family.

The period of six years a struggle of any kind existential, financial, psychic, health they remember it as more than difficult. Now they are facing a new situation where at the Children's Clinic this type of therapy is implemented.

It is clear that the incidence of rare disease in our country in comparison to the number of population is low and with it the experiences in the manner of diagnosis. However the approach needs to be changed.

-It is very hard to reach the final diagnosis. The illness very often is equated to other diseases with the same or similar symptoms. The experiences in other countries show that not only treatment is for free and available for this disease but they go to the limit that they plan the profession of these children and thus providing not only a better quality of life and life without pain – which is the aim of medicine, but also they avoid the expenses on the part of the state, which would be extremely high if disability occurs, which means they also become a social problem- says Dodovski.

Fortunately, now the children are doing well, and what makes these parents especially proud is that they are excellent students, much more advanced than the other children in their surroundings. But the battle needs to continue for all of those in need of help, says Aco adding that now the Health Insurance Fund, besides for them covers the therapy for three other children at the Clinic.

Children Juvenile rheumatic arthritis or Still's Disease is characterized with chronic temperature and anemia. The illness can have a secondary effect on the heart, lungs, eyes and the nervous system. Worldwide with girls suffering from this disease the percentage of recovery is 95 percent because in the period of puberty the changes are more specific, compared to the boys where the percentage of recovery is around 65 percent.

limited possibilities. Some bigger system changes are more than indispensable in this regard – states PhD Momir H. Polenakovikj from the research centre of genetical engineering and biotechnology “GeorgiEfremov” within MANU.

85 PERCENT OF THE RARE DISEASES ARE GENETIC

Regarding the number of types of rare diseases in Macedonia there is a supposition that there are 40 to 50 different diseases. The assumptions are present due to the lack of official registry of types of rare diseases and patients suffering from them. Some are treated as chronic diseases as well, but realistically speaking, all rare diseases

are chronic because they are inherently life-long illnesses. Up to 85 percent of them are genetic and for the greater part very difficult to diagnose, despite the fact that early diagnosis and treatment are a condition for a better quality of life with a certain disease. People suffering from a rare disease which has its own peculiarities are not only numbers and statistics, these are also individual stories with different needs, full of challenges, possibilities, successes, disappointments, twists and falls. Yet, although these diseases are not contagious, these people have a problem finding a job, being allowed into a kindergarden or a school, which makes their lives more difficult and more complicated. Simply, they face difficulties being accepted by the

environment.

Many patients with a rare disease are not identified as rare disease patients; they go to work regularly and no one knows that they have a problem. But part of them suffer physical and mental disability which, depending on the type of disease, how it progresses, how it is treated, whether there is a therapy. There is rarely one and only possible solution. Usually there is the need of a multidisciplinary approach – say from the association “Life with Challenges” which this year will conduct a research in cooperation with “Studiorum” in different aspects in the field of rare diseases in order to develop recommendations for improvement of the quality of life of patients with rare diseases. Raising the awareness on rare

EDUCATED NUTRITIONISTS ARE NEEDED IN KINDERGARDENS

Andrej is bright, smiling and happy child. We met him two days before his sixth birthday, he came to have his picture taken with the presenter Marko on the occasion of the exhibition “Embrace Rarity” on the topic of rare diseases. He was joined by his twin sister Anastasija, and hanging out with Marko was more than fun.

Andrej Arsov suffers Alagille Syndrome and until one year ago he was the only child in Macedonia suffering from this disease. Fortunately, his diagnosis was quickly established, only few months after his birth after which the family got the first instructions for further treatment. Although some positive changes can be sensed on the part of our health authorities, still what is necessary is paying greater attention in the primary healthcare, state the Arsovi family.

-It is necessary for the GPs to be appropriately educated and informed of all the rare diseases that occur in Macedonia in order not to waste time during diagnosis. Also it is important that the municipal social centres be in contact with every family of a person suffering a rare disease and receive timely information about their needs. The kindergardens on the other hand need to have suitable medical staff to observe the children while there, but also

to have educated nutritionists who would prepare a special menu, which is one of the most important in the treatment of children with Alagille Syndrome- says Andrej's father, Blazhe Arsov.

The procurement of medicines from Italy, France, Greece is now in the past for the Arsovi family and Andrej receives regular check-ups at the Children's Clinic. As another problem Blazhe points out the need of proper education of the educational staff in our country in order to provide these children with suitable education.

-You know, no one knows what Andrej will become when he grows up. Perhaps one day he will hold a public function, perhaps he will become the Minister of Health of RM. Should we deny him that right foreseen in the Constitution? – asks Arsov.

Alagille Syndrome is a multisystem hereditary disease. The research show that 75 percent of children diagnosed with this syndrome live on average up to the age of 20, but this survival rate is increasing. Many adults with Alagille Syndrome, who receive the right treatment, have normal productive lives.



diseases in our country, as well as finding an easier way to treatment for patients who are not provided with one is one of the priorities of this Association which counts 200 member patients and parents with more than 30 types of rare diseases. They say that the aim of their activity is achieving long term financing of the Rare Disease Programme which was adopted in 2009 because giving up on it would mean giving up on life, that is accepting shorter life-span.

For a concrete development in this battle for better and brighter future it is necessary to have cooperation among the patients, associations, doctors, researchers and state institutions, underline from the Association. Therefore last year the National Alliance for Rare Diseases of Macedonia was established in which the founders are 12 associations and it is open

for new members with an aim of joining the organizations. The motto of the Alliance is that only together the patients are stronger.

A step forward, which also gives positive signals is also the decision that was adopted at the end of the previous year, and it relates to the increase of the budget for these diseases to up to four million euros, and that thanks to the change in the Law on Excise, according to which one denar from each packet of cigarettes goes to the Rare disease Programme.

-This is truly a big step forward because in the past from that programme medicines were provided only for three patients. Part of those patients who could not afford to pay, received a donation, another part of the patients simply had their hands tied expecting and hoping some



better time, third moved out to countries such as Germany, Switzerland, Italy where they managed to get therapy. For part of the patients, on the other hand, there is no therapy- explains Aleksovska

In the world there are 8000 rare diseases and only for 250 of them there is some kind of treatment (alleviating the symptoms, control of the disease, etc.). Therefore, she adds in Europe and in the States research for medicines for rare diseases is supported with special regulatives for "orphan-drugs". For diseases for which there are no medicines very often an orthopedic aid is needed, physical therapy, psychological help, social services or a personal assistant.



Rare Disease Day[®]

“FACE TO FACE” TOPIC

Living with rare disease is like walking across a mine-field

Vesna Aleksovska

Very often patients try to cover up what renders them stigmatized and excluded from society. They undergo surgeries and different treatments and therapies, but even when the disease is not visible, the pain of failing to be “normal” remains on the inside.

It is said that we define ourselves as persons depending on how we were brought up, what is the environment in which we learn and live, the people who influence us and our behavior, the books which we read and things like these. What I've learned is that what you do not understand as an influence in the beginning influences you the most. For me it was a rare disease, for which, when I first told my friends, they thought it was my imaginary friend, that I was fine and that I was imagining. I did not accept Gaucher as part of my identity for many years. The first time I accepted it as part of myself I was 20 years old.

At the time I had an enlarged belly because of my enlarged liver and spleen, enormously low level of energy because of the low hemoglobin- anemia, I had millions of bruises that would appear after a gentle stroke because of low platelet levels and I had bones that cracked when I would receive a tiny bit stronger hug than usual.

It was then when I realized that I could not ignore what was happening to me and that I should look for help. In Macedonia this disease was not treated and the letters sent to the institutions remained unanswered.

I received a donation through the European Gaucher Alliance and Genzyme, Sanofi Aventis – International Cerezyme Access Program - ICAP.

At that moment 5 years ago my life changed completely. I got a second chance in life. I got a second life, as if reincarnation. Then we established an Association for rare diseases with the help of The Bulgarian National Alliance for People with Rare Diseases, led by their president Vladimir Tomov who has a daughter suffering from the same disease as mine. Never before had I encounter someone like me. When I first met people who suffered from the same disease as mine I felt as if I were home. As if I had been adopted and I finally meet my real family. A family made up of people from all around the world, people who feel like I do, who think like I do, who hurt like I do, who fear like I do, who try to live a normal life just like I do and are afraid to admit that they are different from the others. Because, what is different is always problematic, because, what is different is abnormal and what is different is always something that needs to be fixed...

DIVERSITY IS BEING SUFFOCATED

When I received my diagnosis I was not aware of its meaning, nor its consequences. I was 7 when my parents received the information of the rare disease together with the fact that their child will not live long with such diagnosis. I faced the facts of Gaucher disease when I was at the tender age of 14 and when I could understand what it meant and how I was supposed to live my life in accordance with my disease. I didn't talk to my friends about it because when I tried once they told me I was imagining. I had a so called "invisible" disease. Many diagnosed with a rare disease face this fact of invisibility. Something is wrong on the inside, on the outside, that is physically and mentally you are a normal person with minimal symptoms that will sooner be assigned to millions of other things rather than to one particular disease. For instance, my enlarged belly was not defined by my surroundings as a result of an illness (enlarged spleen and liver), it was defined as a need for diet and exercise. My lack of energy was defined as laziness and my fragile bones were defined as being a "frail" child.

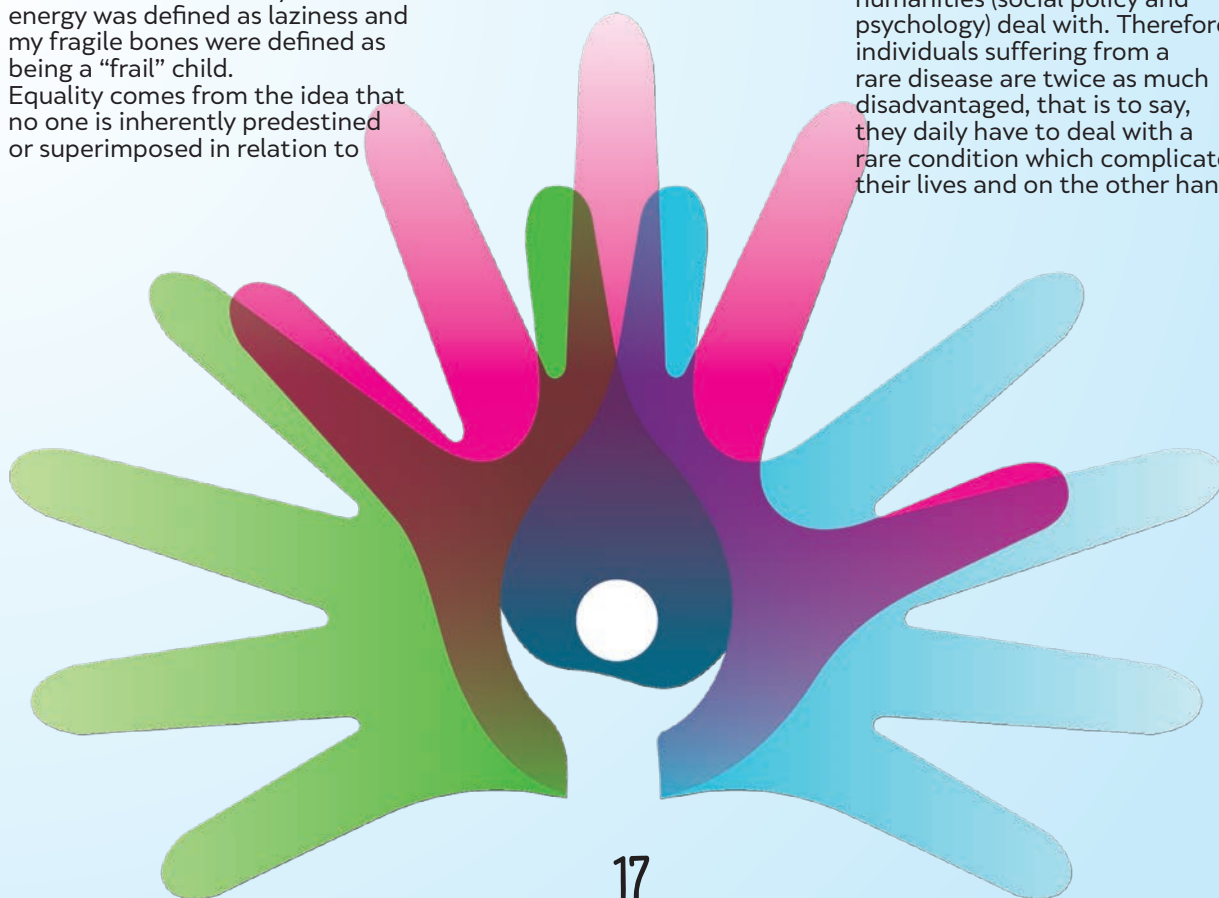
Equality comes from the idea that no one is inherently predestined or superimposed in relation to

the others, that is we are all born free and equal. Yet, many groups are denied this equality. Diversity is often ignored and suffocated by the "normality" model which is based on the physical ability of the so called able-bodied people. Thus, those who do not fit the normality model are excluded, marginalized or assimilated. Today, a lot is being said and done on the implementation of inclusion that accepts and recognizes, rather than the one which stigmatizes and excludes. Today, in most contemporary policy theories the need to recognize in the name of minorities or suppressed groups is being expressed because, recognition marks the understanding of the groups and individuals for what they are and what renders them as individual human beings.

Therefore, Charles Taylor takes as an example the claims of the feminist for the women who in the patriarchy had been instilled into accepting a depreciative image of oneself and they installed an inferior image of themselves on the inside to such a degree that despite the tearing down of the

limits they were not capable of using the new possibilities because they had already accepted the identity of inferiority and powerlessness. This self-depreciation should be purified and the imposed destructive identity overcome in order to open room for the creation of a new identity. That is to say, the wrongful recognition not only ruins respect but also inflicts deep wounds causing self-loathing. This importance of recognition changes the understanding of the individual identity, typical of a human being who discovers its own identity on its own. Inclusion should not lead to assimilation, but towards acceptance and recognizing the universal identity and above all towards acceptance of diversity. Asking for acceptance of equality is asking for acceptance of diversity and its insertion in the so called "normality" model. The lack of awareness and recognition of diversity leads to inhumanity and discrimination.

Rare disease patients are by definition marginalized in the spectrum of problems which medicine, science and the humanities (social policy and psychology) deal with. Therefore, individuals suffering from a rare disease are twice as much disadvantaged, that is to say, they daily have to deal with a rare condition which complicates their lives and on the other hand



they receive very little attention from society by having limited access to diagnosis, treatment and rehabilitation (physical and mental). They remain unaccepted, misunderstood, disrespected and marginalized.

STIGMATIZED INDIVIDUALS

Considering the case of the influence of rare diseases we come to the conclusion that diagnosing a rare disease can lead to different problems with patients themselves and their families, these include: self-blame, divorce, lowered professional possibilities, financial problems in the family, social isolation, discrimination, marginalization and stigmatization. The affected patients and families are in a way forced to adapt to a new “normal” which is simply unfathomable for those who are healthy. Life with rare disease, facing everyday challenges, understanding yourself and the others, every step forwards or backwards is like walking through a mine field. The perception of the stigma because of a disease can significantly influence the individual perception of the patient’s identity. The identity of the patient changes with the disease factor which is being built in the identity itself. It is not only the pain, physical deformities, the failing mental health, regular visits to the doctor, treatment, work, family; it is also the continuous search for quality of living. And when we are in a society which instead of alleviating, aggravates the living of this specific group of people the stigma occurs and these people are limited to a tiny world by the society which renders them “not normal” and refuses to accept them. The media instead of helping in the de-stigmatization of the disease instead do the opposite, by showing images of destitute families and patients who cannot move from their bed or look after themselves. The success stories of people with rare diseases are at the last place, while the tragic stories cover the front pages. The patients are not able to concord with the standards society calls norms and

immediately they become disqualified, they become collateral in society. Erving Goffman, as a sociologist researches these stigmatized individuals and the different strategies they implement in order to deal with rejection, complex life, the overwhelming amount of information that the world projects for them and they for themselves.

SEARCHING FOR “NEW IDENTITY”

A key problem with patients with rare disease is the insecurity and the inability to come to correct and timely information which causes the inability to come to acceptance of one’s own self because “I” changes from one day to the next and from one moment to the next and one cannot know what is the next step or feeling. The person loses the self-respect because of the suffered failures trying to maintain parts of the former “I” of “I” before the disease and confront the transition towards the “new normal”. Very often patients try to cover up what makes them stigmatized and excluded from society. They undergo operations and different treatments and therapies, but, even when the disease is not visible the pain of failure to be “normal” remains on the inside. Rare disease patients differently face the facts which they are presented with by life accompanied by a rare disease which in most cases is genetic. Some patients confront the disease and try to show that despite the disease they can be the best they could. A patient at 35 years of age with a rare disease which causes disability says: “When they first explained what was that that was going to accompany me throughout life I couldn’t understand, I was a child who got an imaginary friend who tortured instead of supporting. While I was growing up I did not allow myself to be different from the others. No one knew about my imaginary friend, I did not want condolence or empathy; I wanted life like the others and more than that. I was the best student and now I work and live life to the fullest and as a whole and perhaps



a bit more as a whole than the others, the “normal” ones. My disease is my friend who enabled me to see things differently from the others, to rejoice differently, to open my eyes and take a deep breath. There are less and less healthy people. My “new normal” is better than their “normal”. Patients who are in the phase of stabilization of a disease, that is when they have in a way the most normal possible life are afraid to show something that would lead to the moment of disease and would show that it is still here, it would show that they are still patients and still different from the others. There are instances of patients who do not accept that they have got a common cold or flu and they don't want or refuse to take a sick leave and to stay in bed at home because this for them is a sign of weakness, sign that they are different from the others and that the disease is always present with them. Therefore they try to be healthy in order to show that they are “normal”, they are just like the others.

There are patients who are simply always looking for their “new identity”, who are constantly on the move, searching for the “new

normal” which will enable them to feel comfortable in their own skin. Other patients, yet, do not feel comfortable and it is as if they want to get out of themselves and be somebody else, they simply give in to fantasy and leave reality behind themselves where they won't have to deal with it. A 15 year-old patient with movement disability and other side symptoms says:

“When I learned about the limitations my disease carries, it was as if I learned about the limitations that I will be facing with every step of my life, in creating my family, the choice of my hobbies, the choice of sport, the choice of education, the choice of profession. My parents had to enroll me in a school which was accessible for me, and there wasn't much choice there, there were two schools and they enrolled me in the one that was closer to home. Then I couldn't choose friends, they choose me, I had to accept that friendship which was offered, I couldn't walk and ask for something else. I couldn't choose sport; I had to choose books and television. They forced me to practice daily and all I wanted to do was to lie in and give in to my despair and flood of limitations and failed expectations. Now I wait...I need a new life... life with which I can face. I want choice, this who I am. In different manners patients with rare diseases are being disqualified and it becomes impossible for them to be fully socially accepted, they are simply stigmatized individuals. Marked with the stamp of illness, whether with a physical deformity or with ailing mental health, with physical and mental limitations, they constantly seek to adjust to their complex and contingent social identities. The image they have of themselves daily confronts the image others have and reflect towards them. The patients, each in its own way implement different strategies in order to deal with their surroundings and daily life and work, so that they could deal with refusal and rejection, with the complex information and the infinite limitations and challenges.

Today, proudly I stand tall and state that I am a patient suffering from a rare disease; it is with

respect that today I say that I have Gaucher disease. Today I am neither scared nor ashamed to say that I am a patient. When they ask me what I do, I don't reply that I have a BA in Economy, nor that I have a 10-year journalist career under my belt, nor do I say that I have worked as a business consultant and trainer; what I say first is that I am a professional patient. For me this means that I am a patient aware of myself and the other patients, aware of the parents of patients, aware of the regulations, symptoms, diagnosis, consequences, but also aware of the possibilities and the progress which is to come. I represent many patients, many brave people who stand with me asking for their rights and I am proud with each parent and patient who has plucked up the courage to come out and tell their story and ask for help. While we keep quiet the world passes by and will pass us by and will not ask us anything if we don't raise our voice.

Many talk about necessary and possible changes, as a patient I think that the first change that we have to make is within ourselves. It sounds like a cliché, but it the initial truth from which we have to start. If we do not accept ourselves, the others will not accept us. If we do not understand ourselves and if we do not understand our needs, how will the others be able to help us? I just want every patient to stand tall and to be proud to be different from the others and not to be afraid of the world, so that the world will not be afraid of him or her. I only wish love for life to win over the love for the material. It is not easy to be a usual human, yet it is harder to be unusual. A rare disease is not a disease which rarely occurs, a rare disease can happen to anyone without any warning and preparation. Therefore we should stand together at the starting line and raise our voice. We are humans, wonderful humans different from the others and that is not something that renders us helpless, it is something that makes us braver and stronger than the others.

(The author is the chairperson of the Rare Disease Association “Life with Challenges”)

“FACE TO FACE” TOPIC

Obstacles as an additional motivation

Maja Nedelkovska

The Olympic champion which in the 60s of the last century was nicknamed ‘the fastest woman on earth’, Wilma Rudolph, reached the top after recovering from infantile paralysis (caused by the polio virus), while the hemophilia was not an obstacle for the career of the famous actor Richard Burton.

The illnesses, including here the rare diseases as well, are a reason for some people to give up on their dreams. For some, on the contrary, they become the obstacle that additionally motivates them to strive to reach success.

STEVEN HAWKING IS BEATING THE ODDS WITH ALS. VENUS WILLIAMS DOES THE SAME WITH SJORGEN'S SYNDROME.

These are only a few examples of famous and successful people who pursued their dream, achieved considerable success and left a legacy behind them. The Parkinson's disease is considered as one of the most common rare diseases with ratio of 1 ill in 5000 and thus, the list of famous people who had this illness is greater in comparison to the others. Johnny Cash, Bill Connolly, Charles Schulz – the author of Snoopy, Bob Hoskins, Michael J. Fox and the pope John Paul II among others, had this medical condition.

The actor and comedian Richard Pryor suffered from multiple sclerosis, Lou Gehrig had ALS. Same as Stephen Hawking. The American President John F. Kennedy suffered from Addison's

disease, while Nick Vujicic was born with the tetra-amelia syndrome. The tennis star Venus Williams has the Sjorgen's syndrome whereas Muhammad Ali, one of the greatest boxer legends of all times, suffered from Parkinson's disease.

The Olympic champion which in the 60's of the last century was dubbed ‘the fastest woman on earth’, Wilma Rudolph, reached the top after healing from infantile paralysis, while Richard Burton had successful career although he suffered from hemophilia.

The illness of the singer and presenter Paula Abdul is called reflex sympathetic dystrophy, the football goalkeeper Tim Howard has the Tourette syndrome, while the famous basketball player Karim Abdul Jabbar suffers from chronic myelogenous leukemia.

LET'S MAKE THE PEOPLE THINK ABOUT THIS!

In a world where the chaos rules in politics, in society and in ecology, how can the human race survive another 100 years, asked one of the most renowned contemporary scientists Stephen Hawking, in order to recognize one month later:

“I don't know the answer. That's why I posed the question-to make the people think about it, to be aware of the dangers we are facing.”

Particularly these thoughts of Hawking illustrate why it is

THE ICE BUCKET CHALLENGE

The campaigns for raising the public awareness, by rule, contribute a great deal in raising the awareness of the public about these diseases and make the public react to the problem. One of the most famous ones was the campaign about the ALS which involved dumping a bucket of ice on someone, which although it had fun aspect, actually was organized for a completely different purpose. The campaign caught the world by storm.

The mass participation in the ALS challenge helped in raising more than 112 million dollars in the form of donations for research about this disease of which in USA alone 30,000 people are affected. It is hard to secure sufficient funding for many of these illnesses and it often happens that a cure is not found – says Andrea Pett Joseph whose son Brandon suffers from Epidremolysis Bullosa which is a form of overly sensitive skin. as a manager of Brillstein, Joseph managed to form a EB Medical Research Foundation thus enlisting the help of Hollywood stars which are clients of the studio in the campaign. Courtney Cox, Zac Galifianakis and Nina Dobrev took part in the campaign raising 5 million dollars for research.

important to raise our awareness about the problems we face as well as the ones that other have to deal with. Likewise, we must stress the importance of empathy and the awareness for the suffering of those we do not know. The rare diseases, regardless whether they are inherited, genetic, chromosomal, can vary from 1:5000 to 1:1,000,000. The public rarely hears about these diseases. Only the closest circle of the patient, the doctors that treat them and the researchers are acquainted with them. The research and clinical research in particular is very rare. The support groups can be inconsistent. Finding funding for the research, in most cases, is a slow process.

When a patient with rare disease is in the focus of the broader public, it means that things have moved from standstill. In this case, and by sharing this awareness, the society becomes acquainted with the diseases. In this manner we raise the awareness, we increase the funding, journalist stories are going round, interviews are given, research is organized, better treatment is sought for and finding a cure is a hope and inspiration.

In the media and on the internet, by doing little research you come across cases like that of

Sarah Atwell who suffers from neurofibromatosis. Due to this problem she was bullied by her classmates. This young, gentle and sensitive woman opened up about her feelings in a video on YouTube. Her story was later retold by Discovery in “The Girl With Half a Face”. Before the appearance of the brave video of Sarah Atwell how many people knew or had heard about neurofibromatosis at all? Perhaps 10,000 people? Several months after the broadcast of the video, in 2013, this number increased to several million people.

FRIENDSHIP AS FANTASTIC AS CHOCOLATE



The eight year old Dylan Siegel wrote the book Chocolate Bar two years ago, which was sold in 25,000 copies, thus making profit of over 1 million dollars. Why did Dylan write the book and what did he do with the money? In the book Dylan described his friendship with his best friend Jonah who is affected by a rare disease. Dylan said his friendship is fantastic like chocolate. He wrote the book in order to help Jonah and thus the book Chocolate Bar is available to all of those who want to express their support and it is also an example of doing a good deed.

“We hope that this book will help the children in every part of the world to see that their big ideas can cause great and positive changes in the world,” – reads the webpage of Dylan’s book.

All funds that have been raised so far and those that will be raised in future will go directly to the Research Fund at the University of Florida which was created especially for Johas’s condition- GSD-a rare liver disease.

“FACE TO FACE” TOPIC INITIATIVE FOR AWAKENING AWARENESS- “EMBRACE RARITY”

FOR A MAN NOT TO BE ALONE IN ONE'S FIGHT!

Aneta Risteska

The role of Public personas in initiatives important for awakening the social awareness is huge, especially because they have an audience that believes their statements and actions, state the popular personas who accepted the invitation of “Face to Face” to be part of the photography exhibition, the aim of which is greater awareness for the life and needs of people suffering a rare disease.



Gjurica Kaeva and Beni, “Blue Lips”

“Of course I’ll come, just tell me where and what time”, “Count on me”, “I could do it today”, “Not a word. I’m there.”

These were just a few of the replies of the popular personas that the editorial of “Face to Face” contacted in order to invite them to be part of the exhibition “Embrace rarity” which put in its focus people suffering from a rare disease. Gjurgica, Vesna, Viktor, Iva, Igor, Slavche, Dejan, Andrej, Ana-Marija, Azemina, Marta, Viktorija, Boja, Markijan did not hide their excitement from the possibility to have their picture taken with Beni, Tanja, Bubo, Dani, Kristna, Toni Zen, Indira, Marko, Vera, Ognjen, Pece, Rebeka.

Without hesitation and completely selflessly they accepted the initiative of the activism platform “Face to Face” to bring about the issues related to people living with rare diseases and their treatment here. Smiles, excitement, a sip of coffee, a little bit of make-up, many denim ribbons (the symbol of rare diseases) warm and relaxed atmosphere; quite inspirational.



Marko Noveski and Andrej Arsov, "Do Hurry up!"

These were hours of genuine meetings, telling of life stories with happy or less happy moments, remembering old friends, building new relations. Tomi behind the camera, through Neshko's concept "froze" every moment that has to carry the individual story of our fellow citizens who heroically face the challenges that rare diseases carry. From time to time the other members of the "Face to Face" team Tina, Ane, Maja, Sandra, Zharche "meddled" in the work with their creative suggestions, and the right hand and logistic for all sessions were both Irena and Viktor, the main "culprits" for the make-up and the look of most of the photographed faces. In the end we left the work to Zoki, our designer, whose "inbox" is full of praises, and to Ruki, credited for the creative interventions on the cover pages of "Face to Face".

SILENCE CAN BE A CRIME

All the public personas who accepted the invitation to participate and who are known for their humanitarian gestures say that this action has left a strong impression on them.

-I have experienced this engagement as a blessing. Perhaps because I also have experienced it personally. When I was 11 I faced a rare disease in the rib-cage which caused scoliosis and obstruction of the lungs. Thanks to the promptness of my parents and the

medical care I recovered and what I have left now are only memories which burn in the back of my mind reminding me that every such action demands public support and recognition so that a person is not alone in their struggle- says the presenter and columnist Ognjen Janeski, who is on the cover page of this issue of "Face to Face"

The great supporter of our platform was photographed with the young Azemina who suffers from the rare disease Gaucher. He says that they both left for home with new knowledge from the time spent together.

-I learned a lot more about her rare disease and transferred experience that the smile is the best medicine for the greatest

pains – spiritual and physical. She transferred on to me childish fever which we constantly need to foster. I am very grateful for that- says Ognjen

The role of public personas is great in such initiatives, he adds, especially because each of them has their own audience who believe in them.

-The silence of public personas is a serious "crime" towards the audience. In our society, in general, I can say that the appeals from public personas for charity and charity works is at a high level, but only in the charity part of the existence of their public persona and not in other aspects where they need to stand out as concerned citizens about the events happening around them. Because, public personas are above all citizens and use the same counters as the others. There is always time, just remember – Mother Theresa also had 24 hours at her disposal just like any of us and that's it- explains Ognjen.

LET'S REMOVE THE STIGMA!

Petar Mladenovski, Macedonian musician, member of the Macedonian ska-punk band Superhiks, known as Pece, defined the participation in the preparation of the exhibition "Embrace rarity" as honour and pleasure.



Igor Parmakovski and Kristina Arnaudova, "I understand you!"

-I don't often get such invitations, and I'd love to be part of such initiatives more often, of course if we are not too busy in certain periods. Nevertheless, this is a great action the aim of which is obvious and clear- let's approach all these people who are "rare" as any other person we know and communicate with, hang out, work with. Let's remove the stigmas and let's do that as soon as possible!- says Pece. Each public person which carries a bit of soul and sense should be part of more such activities and initiatives, he adds.

-However, I've had situations in which I had to refuse an invitation for similar actions and encountered total misunderstanding from those who have invited me and even been hung up on and I had to refuse due to valid reasons. Therefore, it is not always easy to be a public person. When half of my colleagues would support at least one such action a year, we would have a great score! - claims our musician who was photographed with the teenagers Viktorija Penova from Valandovo who suffers from FOP and Marta Vasikj who suffers from Strumpell



Dejan Angeleski and Indira Kastratovik, "Challenge"

Syndrome.

On the question whether in time when racing for existence, do humans become less socially responsible and have less regard towards the more vulnerable groups, the Macedonian musician replies that this is a matter

of individual awareness and consciousness

-One cannot get angry with people, taken collectively, in conditions of racing for existence. What are we talking about social responsibility of the individual when society itself has long ago given up on the individuals themselves? These parameters have been misplaced for a long time and many things in the system need complete review and re-organisation. Firstly, the system itself and the state should care for the most vulnerable and with it each individual should help- he says.



Slavche Shopovski and Toni Zen, "Trembling"

GETTING OUT OF THE PERSONAL AND LIMITED VIEW

Positive response comes also from Vera Miloshevska, vocalist of our famous music ensemble "Ljubojna", who was photographed for this initiative with the 13 year old Ana-Marija who suffers from RETT syndrome. She says that "Embrace Rarity" is one of the actions that aim to open the public eyes and put it face to face with other people's problems outside their personal limited everyday view.

-That is, actually the main contribution that a public person could provide. Personally I support the initiative that helps face the problems of those that are "the quietest" in society and face countless obstacles in everyday life



Ana-Marija and Vera Miloshevska, "Embrace rarity"

in order to find even the smallest of solutions. The least of help is an alleviation. In our country attention is fully absent from the greater part of happenings and of the modern human problems

today, in general. Thus, when the basic human rights are still in danger, what is left for the marginalized groups of people. Basically, it all comes down to the human factor because not enough



Bojan Chunde and Rebeka, „1:10.000“

dedication to the problems because of lack of finances (as the most often used excuse of the institutions and individuals) still is not a starting point. The starting point begins from the interest, taking initiative, developing adaptable legal solutions, in the end of simple compassion-she says.

USING FAME FOR EXALTED AIMS

Bono Vox, David Beckham, George Clooney, Elton John, Bill Gates, Angelina Jolli, Mia Farrow, Ben Afflec are only few of the worldwide household names that participate and organize great humanitarian actions in order to help various marginalized groups.

They organize charity concerts, buy medicinal equipment, hand out blankets and survival equipment in alarming situations, establish foundations, shave their heads as sign of support for sick children, cover treatments, buy houses and raise public awareness. But, this dedication and awareness is no stranger to the region here, and one of the many examples is that of the famous Serbian actor Dragan Bjelogrljik, who a year ago organized a get together for children suffering from Hunter syndrome, and with such charity gesture turned the public attention to the health problems these seven children face in Serbia, whose treatment was not financed by the state.

In this endeavour Bjelogrljik was followed suit by all the other actors from the film "Montevideo" in order to send a message to the Ministry of health for greater care for these children. For the aims of this noble mission they played more than 30 charity matches. Hunter syndrome is a rare genetic disease and a disease of the metabolism which does not have any outward consequences on children. After birth they seem healthy, but due to lack of enzymes which break down the sugars into simple sugars, organs start to fail and very often there is damage to the central nervous system.

“FACE TO FACE” TOPIC

Learn from the people with rare diseases!

There is no better way to advance the proper practice of medicine than to give our minds to the discovery of the usual law of nature, by careful investigation of cases of rarer forms of disease, wrote William Harvey, English physician.

In a letter written in the distant 1657, the acclaimed English physician William Harvey who made his name by accurately describing the blood circulation emphasized the great significance of the rare diseases for the advance of medicine.

“Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows tracings from her workings apart from the beaten paths; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the usual law of nature, by careful investigation of cases of rarer forms of disease,” wrote Harvey.

For example, the research of Fanconi's anemia lead to broadening

of the understanding of the pathological mechanism of cancers and their resistance to chemotherapy.

The research of the Wilms' tumor, a rare form of cancer that affects the young and the newborns, nowadays it is pointed out as a model for understanding of genetic, epigenetic and molecular biology of the pediatric cancers and the cancers in general.

The recent studies have demonstrated that the new treatment options for cancer achieve biggest effect in the rare forms of cancer, where by stratification of the common forms of cancer, by using certain agents for molecular subset of the illness, it is determined where the therapy would achieve the greatest effect.

The rare forms of cancer have been classified in the group of rare illnesses, such as they are defined in the EU and the European Medicine Agency (EMA) as illnesses that have a prevalence of less than 5 cases in 10,000 citizens.

After 10 year of the implementation of the Orphan drug directive in EMA, the agency has gathered significant data on the prevalence of rare diseases according to the received

applications for medicines, which can be classified as Orphan medicines.

This data is available to the public. Unfortunately, there is no official registers in Macedonia whereby the official number of cancer patients would be known and especially the number of patients who suffer from rare form of cancer. Around 4.3 million people in the EU are affected by a rare form of cancer i.e. around 500,000 patients each year. Individually, each of the total of 198 identified cancers is considered as 'rare', but that is 22 % of all the forms of cancer diagnosed in the EU countries and the EU candidate-countries each year, including here the rare solid tumors in the adults (13 %), the rare forms of hematological tumors (8 %) as well as the pediatric cancers.

Late or wrong diagnosis, lack of appropriate therapies and clinical expertise, limited number of clinical studies due to the small number of patients, lack of interest by the pharmaceutical companies for development of new therapies due to the small market, are some of the challenged that these patients are faced with.

In order to achieve greater inclusion of these patients in the health system research collaborative groups are needed as well as patient groups that together with the regulatory bodies would enable greater access to therapy for the rare forms of cancer as well as approach to new clinical research.





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Every new day is a new promise to be there for you and for all of those that make your day better. We have the experience, the knowledge and the true resources to provide you the energy you need for every moment of your life.

Human side of business

Verica Jordanova

The comprehensive analysis done by experts undoubtedly indicates that the inclusion of the employees by the company leads to greater productivity, competitiveness and growth. Precisely this is the goal of every economy.

Being on the threshold of a new period in my career, lately I have been searching for inspiration and tips for success in the autobiographies of the founders of some of the internationally acclaimed companies that have already established themselves as brands in the awareness of the consumers. One of them is Howard Schultz, the founder of Starbucks, which is probably the most famous and highly successful chain of coffee shops in the world. Telling the story of his life, from growing up as a poor boy to an entrepreneur who while traveling through Italy came up with the idea to introduce the good cup of coffee in the USA, he reveals one great truth - the human factor must not be forgotten in the race for profit and skyrocketing sums. The human aspect of every business is key for the longterm success. Perhaps it sounds like a demagoguery in a time of global financial and economic crisis when many of the companies have gone

bankrupt, millions of people have lost their jobs and their properties as well and whole cities have been destroyed as a result of the downturn of the economy.

However, in his book *Onward: How Starbucks Fought for Its Life without Losing Its Soul*, Schultz once again reminds us that people are not mere numbers at the end of the day.

'Although these numbers are one of the scales for measuring the success of our company, yet those are not the thing that makes Starbucks really successful, at least not according to my definition.

As a business leader I have never looked on the guests as a means for victory and making money, they have always been a means for building a big, sustainable company whose aim always was to achieve a balance between profit and social awareness. No business can ever be good for its shareholders without previously creating a good environment for everyone that is affected by this business. For us, this means doing the best we can to treat everyone with respect and dignity, from the farmers that produce the coffee to the baristas, the consumers and the neighbors. I understand that the strife to achieve profit without sacrificing humanity sounds lofty. However, I have always tried not to stray from this goal - even when Starbucks and I lost our way...Not only the people's awareness about the prices continually increased, but they also became more concerned about the environment, the health and were moved by the ethical codex. The consumers demanded higher standards from the companies they cooperated with, including Starbucks.'

Fortunately, the theories of capitalism such as they were set in the beginning of the XX century, have long been part of the past. It seems that the world functions

today in a hybrid economy where there is intertwining of the market of capital and the cooperative economy, which includes ever more so the concerned parties.

Of course, one of the most concerned parties or stakeholders, as they are called, are the people regardless whether they are employees, shareholders or consumers. Their awareness that the companies must not behave like money crunchers has already been raised. For example, the socially responsible companies that do not pollute the environment begin to stand out from their competition by putting the so called eco labels. By doing so, on one hand they emphasize that they are responsible and on the other hand, they target those consumers who do not want to use the products of the companies that destroy nature at the expense of production. So, at the end of the day, these companies actually are introducing innovations by adapting themselves to the new market conditions - more and more consumers choose who they will purchase products/ services from. They again take into account the sales and with it, the profit, by intelligently selecting their consumers.

Another example which pinpoints to resurgence of the human dimension of business is the increasingly popular theory of economic democracy which aims at increase of the involvement of employees in the business itself via employment shareholding, cooperatives, crowd funding and other forms. Although perhaps this might sound unusual to those of us who have lived in a socialist system, this is a growing tendency in the Western democracies. The number of European companies that have employee shareholding has increased by 10 % in 2013 compared to 2009. In addition,

in 2013 that number was 2 % of the total number of companies in the EU. Just to be clear, this is not done out of pure philanthropy. On the contrary. The detailed analysis conducted by the experts clearly indicates that the inclusion of the employees in the decision making of the company yields greater productivity, competitiveness and growth and that is the goal of every single economy. The clever owners of capital who know this should not have problem in placing their employees on a higher pedestal.

An old and at the same time new term that is being frequently used nowadays is social entrepreneurship. In its broadest sense, this term means return of part of the profit to the community, for the common good. A rather global trend that fortunately starts to be

implemented in Macedonia is the increase of the practice of social entrepreneurship among the young entrepreneurs. The growing start-up scene in the world and even in Macedonia opens numerous opportunities for creation of a new generation of young entrepreneurs and businesspersons who will have the social entrepreneurship ingrained in their nature. If the various initiatives that are undertaken in this field flourish in earnest, we are hoping to see a more human aspect of the business in the next decades. This year for the first time Macedonia is also part of the European initiative "Social Entrepreneurship" and Impact Hub at the Vienna School of Economics and Business. Their mission is to promote the social entrepreneurship among

the students and the start-up companies as an efficient way for founding of responsible and sustainable businesses.

With the innovative ideas being at the heart of its focus, the newly formed initiative Inovativnost.mk (www.inovativnost.mk) on its webpage tackles the issues that deal with new ways of thinking, giving the young, creative minds a chance to protect the environment by using innovative approach. At the same time, emphasis is also put on the employees, the shareholders, the clients and the consumers i.e. The initiatives that put the human first as well as its values and potentials that have to be highly valued...so as not to lose our way...as Shultz, the founder of Starbucks, puts it.

(The author is founder and editor of Inovativnost.mk)



UNrecognised partnerships

There is little communication between citizen associations and the business sector, and that in great part is due to the lack of initiative on the first, but also to the lack of interest of companies for corporative philanthropy, as has been shown in the research by "Connect"

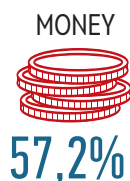
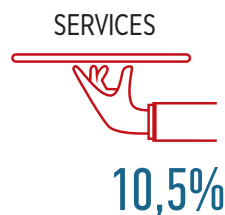
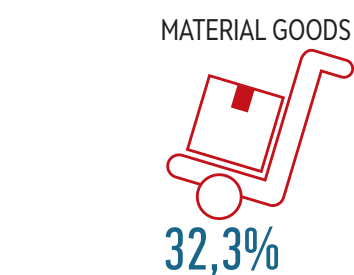
Support for treatment, for a sports event, direct help for poor citizens, help in humanitarian disasters (such as floods and earthquakes), but also support for building religious buildings are the cases which are the top five on the scale measuring the investments/donations of companies in Macedonia.

This is shown in the research carried out by "Connect", titled "Between the desires and reality: Corporate philanthropy with special focus on the cooperation between the business sector and the civil sector".

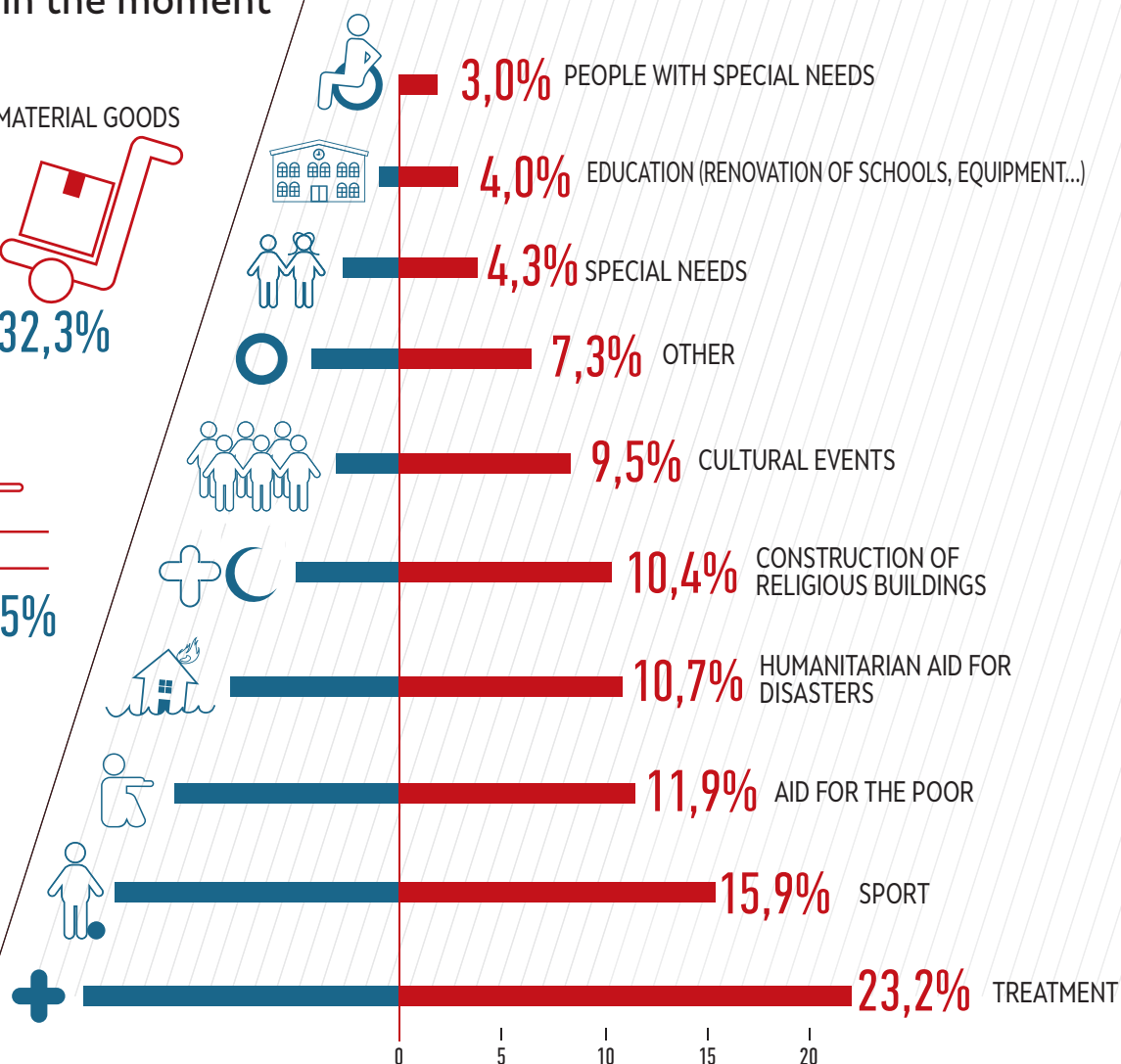
The results also state that there



Companies donate what is easiest and most suitable in the moment



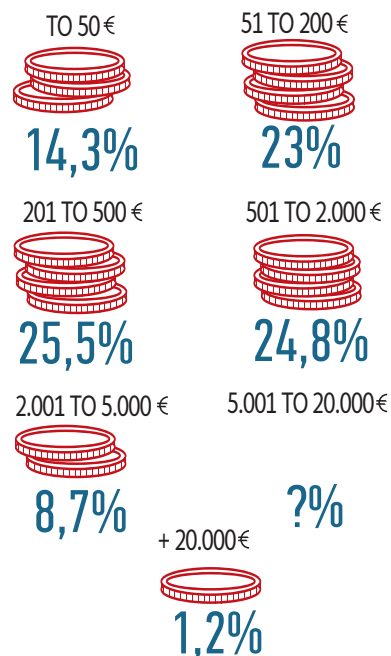
Mostly they donate in humanitarian aid



is little communication between the organizations and the business sector and that is so in the greater part as a result of the lack of initiative on the part of the first. Only a part is included in mobilizing resources from the business sector and even smaller is the number of those that do that systematically and continuously. The research has shown that very few of the companies in the country have received requests for donations from the civil sector. Another conclusion that was reached by this study is that in the current conditions the resources that are available from the business sector cannot provide financial sustainability of the civil sector. An important part of the business is not interested in corporative philanthropy whereas the other part gives relatively small donations. At the same time, only few of them are allocated to organizations. The physical

persons who are the most frequent demanders, religious communities as well as sports and cultural events are the competition for the civil sector. The conclusion of the study is that for a great part of the organizations involved in mobilizing funds from the business sector these are temporary or ad-hoc effort which has not been strategically thought out and is not systematical or continuous. The organizations have no interest in requesting donations from the business sector because they consider "it does not pay off", that is to say that the donations which they will receive are low and not enough. Still, even under presumption to improve the strategic approach of the organizations it is obvious that the chance to get donations from the business sector is conditioned that is to say it depends on the field in which the organization works.

Estimated total value of donation on annual level



Companies know what a citizen organization is, but they rarely cooperate with them

DO YOU KNOW WHAT IS CITIZEN ORGANIZATION

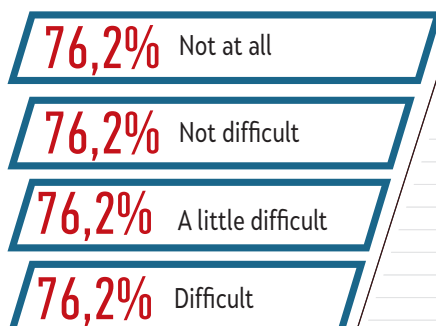


Citizen organizations have an opinion that it is difficult to get donations from companies

DID THEY ASK FOR PROMOTION?

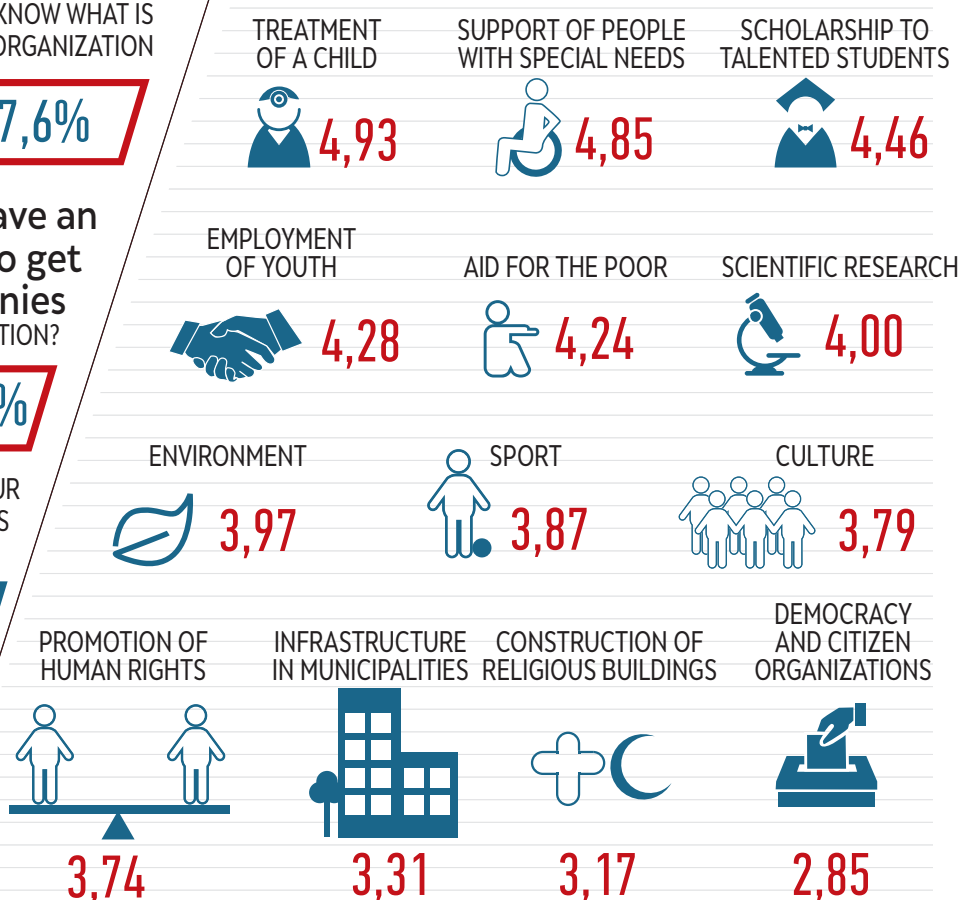


HOW DIFFICULT WAS IT TO REALIZE YOUR COMMITMENT TO THE COMPANIES THAT GAVE YOU A DONATION?



What of the following do you think it should be supported with donation?

(Estimated assessment from 1 to 5)



INVISIBLE BARRIERS: LIFE WITH A FAKE PASSPORT IN EUROPE

Christof Moser

In Switzerland and the rest of Europe, border control has become the basis for a business worth billions for organised crime. Human trafficking and people smuggling are – ahead of even weapons and drugs – the most lucrative branch of the global black economy. Swiss street paper surprise speaks to a number of people who have been forced to use fake passports in the hope of securing a better life. All have the same story to tell; the story of invisible barriers surrounding Switzerland and Europe which, whether legally or illegally, can only be overcome with one thing: money.

Meet Edita* from Albania, who has to hand over her savings every few years for new papers. Yazhen, from China, who spent two months' pay on his fake passport. Sarah from Zurich, who had to marry the Angolan father of her daughter so that he could visit them in Switzerland. And Nina, also from Zurich, who wanted her Egyptian cousin's help to look after her dying father and came to grief with the immigration authorities

These four people all have the same story to tell; the story of invisible barriers surrounding Switzerland and Europe which, whether legally or illegally, can only be overcome with one thing: money.

There were times when passports could mean the difference between life and death in Europe. Adolfo Kaminsky was part of the French Resistance against the Nazi occupation. His life story - told in the book written by his daughter Sarah, "Adolfo Kaminsky - a forger's life" - tells of how he and four others made forged identity papers around the clock in a tiny attic in Paris. In doing so, they saved the lives of thousands of people.

"We lived outside the law for one simple reason: to save people's lives. Out of necessity," Kaminsky said in a 2011 documentary. "I always had the feeling that if I slept for an hour it would cost thirty children their lives."

Kaminsky, now 89, went on to support the Algerian war of independence and dissidents who fought against apartheid in South Africa, Greece's military junta and dictatorship in Spain and Portugal. Incidentally, the master forger considered Swiss passports to be his biggest challenge. At first Kaminsky couldn't produce the lightweight card which is both firm and very bendy. Then it came to him one night how he could recreate a similar feel.

CONDEMNED TO CRIME

In contrast to Kaminsky, who never asked for payment for his services, today's barriers of migration have become the basis for a business worth billions for organised crime. Human trafficking and people smuggling - ahead of even weapons and drugs - are the most lucrative branch of the global black economy.

Edita will shortly spend several thousand Swiss francs of her hard-earned money so that she won't be without papers and lose her already precarious life in Switzerland. Following credit fraud in Albania in 1997, when thousands of people lost all their savings, the "Lottery Uprising" broke out. Two thousand people died and at the end of it all the government was toppled. Edita, then aged 26 and a trained nurse, decided to flee with her husband. They gave three thousand dollars to a corrupt Albanian civil servant for two Schengen visas. When the two of them arrived in Switzerland, they applied for asylum. They were rejected. "For a residence permit our wish for a better life was not enough, of course," says Edita in broken but understandable German. She didn't want to go back to Albania under any circumstances. The Albanian couple found out about a Greek consular official who was selling fake passports. They paid him another two thousand dollars each, the rest of their savings. So Edita and her husband became, on paper at least, EU citizens and were allowed to live in Switzerland.

Today Edita works as a cleaner and her husband as a temporary worker at a construction firm. She would love to work as a nurse, the profession she trained for, but her diploma isn't under the same fake name as her passport. The fear of being found out permeates their whole life. "It's like you can't breathe", Edita says. And she and her husband will have to spend all the money they put aside when they next need to renew their passports. A fake passport has to be continually re-forged - renewing it officially is risky. "For Switzerland, we are criminals. So we are forced to work with criminal networks to be able to live here", Edita says. "But we don't want to hurt anyone or exploit anyone, we just want to work." When Edita wakes up at night she is bathed in sweat from a nightmare that her web of lies could be exposed. "We would lose everything, including our pension insurance."

THE CONSENSUS IS CRUMBLING

A passport determines your prospects in life, a fact that is often easily forgotten because the freedom to travel is something most take for granted. With an EU or a Swiss passport, every country in the world is accessible and a visa is only in rare cases anything more than an administrative hurdle. In an emergency, people in Switzerland would even be allowed to travel from Spain to Morocco with an identity card, while people coming the other way die at the European barriers or in the Mediterranean.

British historian Peter Gatrell has calculated that 175 million people have had to leave their homes since the end of the Second World War. This year alone, 140,000 people have come to Europe via the Mediterranean. Most of these come from Syria and Iraq or from sub-Saharan countries such as Sudan, Eritrea, Mali or Somalia.

These are countries where we have waged wars, countries to which we supply weapons, to one, to the other, to all of them. Even today when it comes to refugees from the war in Syria, the social consensus which guarantees them a right to asylum, is crumbling. Not to mention those termed "economic refugees". Why do we give more help to people fleeing actual wars, who are threatened by our weapons, than we do to Somali fishermen who have lost their livelihoods because our fishing industry has taken all the fish from the Somali coast?

For the dream of a Europe without borders, which the economy with its hunger for cheap labour has made possible, those who are not allowed to become part of this dream pay a high price. They are locked out, warded off, shoved aside, they drown off the coast of Lampedusa, die at European border fences, are picked up, sent away, deported. Either they die, or they live in the shadows of illegality.

THE FATE OF THE MASSES

Up until the 19th century, emigrants and immigrants were simply migrant workers - those who are disparagingly called "economic refugees" today. The first people in European history to be perceived and dismissed as refugees - migrants whose very existence was under threat - were eastern European Jews from 1880. Fleeing from pogroms in Russia, they emigrated to western Europe where they were seen as inferior by the native western European Jews. Nazi ideologues later used the stereotypes resulting from this internal Jewish altercation to establish their construct of the inferiority of all Jews. But already following the end of the First World War, as the Austro-Hungarian, Ottoman and Russian empires were swept away and replaced by nation states,

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migration became the fate of the masses. Since then, a competition has been raging between governments over ever stricter, more complicated and arbitrary rules, characterised in their essence by the nation-state thinking of the 1920s, to control, if not stop, migration. Europe, the cradle of the Enlightenment, stage of liberal revolutions and human rights, is being sealed off with dubious success. Just like with the war on drugs, the harder the authorities clamp down, the bigger the illegal business grows.

THE INCONSPICUOUS CHINESE MAN

Yazhen has a wine-coloured EU passport, issued in 2007, and lives in the twilight zone of undocumented workers. He is not tolerated, but neither is he unwelcome. According to his passport, he comes from Macao; actually, he is from Fujian, a province in south-east China. He doesn't speak a single word of Portuguese, nor has he ever been to Portugal or Macao. The details in his passport belong to a person who lives in China. And Yazhen lives their life in Europe. He told a reporter from swissinfo.ch how he came to Switzerland: he entered Europe in 2009 via Hungary with

a tourist visa, discovered while he was there that there was work in Switzerland, and landed as a tourist with a Schengen visa in Bern.

When the visa ran out, Yazhen needed new documents. There are phone numbers in circulation among Chinese undocumented workers which are helpful for such problems. After a few calls and a fee of 3000 francs, three months later he was holding a brand new passport in his hands with "União Europeia - Portugal" in golden letters on the front.

Chinese people with Portuguese passports are inconspicuous - Macao used to be a Portuguese colony. Yazhen has been working ever since in Switzerland, without a contract and without social insurance. He gets 70 francs for an eight hour day in a Chinese restaurant near Bern. That works out at 1500 francs per month. From this he pays 300 francs for the small flat he shares with another Chinese undocumented worker. Yazhen thinks his salary is ok - he knows Chinese people in Switzerland who don't earn any money at all for their work. One burden for Yazhen is constant fear of the police. "If they catch me, I will be sent back to China. I just want to earn money and not cause any problems", says the nearly 30-year-old. "I'm only here illegally

because there is simply no other way".

50,000 FRANCS PER PERSON

Around 1000 Chinese undocumented workers like Yazhen work in Switzerland, estimates the Swiss Coordination Unit against the Trafficking in Persons and Smuggling of Migrants of the Swiss Federal Police. Large-scale raids constantly throw up smuggling networks. At the start of 2013, there was a national police operation against a human trafficking ring which was illegally smuggling people from China into Switzerland. 349 suspects were stopped and investigated, and 57 people were arrested. Smuggling rings have been discovered in Spain and France who were charging up to 50,000 euro per person to smuggle Chinese people into Europe.

When we Europeans talk about freedom, we mean our freedom. Our values. Our standards. And forget the lack of freedom of others. An injustice which, the longer it goes on, is also becoming like a prison. The lack of freedom of others eats its way into our freedom, poisons it, makes it fragile, dissolves it. The post-9/11 anti-terror laws were the start of a global security state; at the EU's external borders, military technology is being used against



migrants. If we ever really believed in the values which we like to call our own, then we are now betraying them on a grand scale. The borders that we draw can't be overcome by friendship or love. Even having children together doesn't help people on different side of border walls or legal ramparts. The world is divided, classified into inside and outside, into Schengen and non-Schengen, into positive third countries (without visa) and negative third countries (with visa). But the disorder in human lives doesn't adhere to this.

ONE PERSON, ONE MIGRATION RISK

Sarrah, 35, a teacher from Zurich, got to know the father of her now 14-month-old daughter four years ago in South Africa. Daniel is originally from Angola, has a residence permit for South Africa and a job there. Daniel can't visit his daughter in Switzerland because the Swiss Embassy in South Africa has rejected his visa application. The authorities consider the risk that he won't leave Switzerland again is too high. 300,000 francs is how much Sarah or Daniel would have to have in their bank account for him to be allowed to remain in Switzerland. As a single mother, Sarah lives off 2,800 francs of child benefit per

month; only with unemployment benefit would she have the income of 4,000 francs per month which is currently needed for a father from overseas to visit. "If I am registered at the regional employment centre, people tell me that I can forget it", Sarrah says. What options does she have left? "Just marriage. But I never wanted that as a means to an end." Even when it is a question of life and death, the bureaucratic machinery is still unrelenting - and people are still fundamentally suspicious. Nina, 33, an employee from Zurich with Egyptian roots, was born and grew up in Switzerland with a Swiss passport and tells a similar, yet completely different story. She tried to get a visa for her cousin from Cairo. "My father was seriously ill and supporting him at his hospital bed here in Switzerland was too much for me on my own", she says. Nina sent the Swiss Embassy, as requested, a written invitation to her cousin with the assurance that once the visa ran out she would take her cousin back to the airport. She also sent three payslips as proof that she could cover the possible costs arising from the visit. She confirmed in writing that she would cover all insurance costs. And she included a letter from the hospital confirming the condition of her father's health, who at that time was on a ventilator and was not conscious.

But the visa application, for which she had paid 150 francs, was rejected. The reason? Unreliable documents. "I was so angry that I could have sent the immigration authorities a photo of my father in hospital and asked if at least these 39 kilos of human were reliable enough," she said.

Real-life stories of people who become a risk as soon as they land on the desk of a civil servant in the form of a visa application. The visa codex of the EU, which Switzerland is also tied to, thanks to the Schengen Agreement, contains, according to a spokesperson from the Federal Office for Migration "a non-exhaustive list of documents" which an applicant can be asked to provide. And depending on their "socio-economic situation" in their home country, even more papers, records and evidence are required so that "potential migration risks" can be gauged.

"For some individuals" who are known for their integrity and reliability, the authorities can waive the "submission of one or more of the supporting documents". In other words, they can turn a blind eye. In "justified cases" the Office can request additional documents, the spokesperson explained, adding in brackets: at their discretion. A more striking expression of arbitrariness would be hard to find.

*All names have been changed.



(UN)USED OPPORTUNITIES

Maja Keramitchieva

In the past six years several reports and documents have been created and published which abound in proofs that lead to the existence of serious delay and partialness in published information on the part of the National Agency for European Educational programmes and mobility-states Aleksandar Kolekesi from the Macedonian Centre for European Training.

For the implementation of the programme "Erasmus Plus" which represents a combination of all the current education, training, youth and sport programmes of the European Union and began in January 2014, the European parliament allocated a financial foundation of 14, 7 billions of euro or 40 percent more from the present budget framework. This programme for mobility, cooperation, innovations and practices is also open for non-EU member citizens, including Macedonia as well.

Horizon 2020 is also an opportunity for an international experience in the field of research and career, which is a financial instrument of the EU with which research and innovations are supported with end goal economic prosperity, creation of new jobs and competitiveness. The programme has a budget of 70 billions of euro and it will last until 2020. A contract for the participation of Macedonia under equal conditions and rights like the EU member countries was signed in Brussels in July last year. But how much will the Macedonian students and researchers take advantage of the opportunities offered by these programmes?

NOT ENOUGH INFORMATION FOR STUDYING ABROAD

Informing on these opportunities is carried out only through one informative lecture in the course of the academic year and this

type of information is also scarce in the media.

According to Anastasija Dimitrova, a student who has spent a semester in Erasmus, the lack of information was seen through her personal experience. She says that there is little information for studying abroad for this programme as well as for many others. The best way to reach these programmes is through searching the appropriate web pages and contacting people who have already participated in a similar exchange.

For the student Aleksandra active search is also the best way.

- All the programmes have their web-pages where in detail it is explained what is being offered, what are the criteria and what is the application procedure- says Aleksandra, who with her individual search has come across the necessary information for these programmes and decided to seize the opportunity

DELAY AND PARTIALNESS

From the Macedonian Centre for European Training, talking about their experience in the field, regarding transparency of informing students, claim that in Macedonia there are certain public events organized on the part of the National Agency which is a state agency and has an activity among others to inform and disseminate practical data for participation in the programme in the country. In this regard we can express

EVERY YEAR AROUND 30 STUDENTS GO TO FRANCE

-For many years a Fair of studies in France is organized in Skopje which enables the Macedonian audience to meet representatives from the French universities, in order to inform it about the offers of study programmes as well as to get answers to all questions related to studying in France- explains Suzana Peshik from the French Cultural Centre. All the interested parties can, also, find information on the web pages of the French institute in Skopje, the French Ministry of Higher Education and Science and of course in the department Campus France within the French Institute in Skopje which helps students to find the desired programme and offers them the necessary information to prepare them to study in France. The number of applicants is not limited and each year between 25 and 30 students leave to study in France.

serious reserve on the quality and timing of the shared information. That is because in the past five, six years many reports and documents have been created and published on the public policies that abound in proofs that serious delays and partialness exist in the publishing of information on the part of this agency. For example, although the EU call has been published on October, 2, 2014 (Official Gazette of the EU C 344/15) it was not published in Macedonia until the end of November. An additional risk to the timely and quality informing of students from the National Agency is its professional and administrative capacity, especially bearing in mind the fact that the European Union has once previously already suspended its work for a period of two years- says Aleksandar Kolekeski from the Macedonian Centre for European Training. He also adds that it would be best if the universities themselves, especially state universities, increase their transparency in the part with the criteria and availability of information for mobility of students and start applying quality promotion of the opportunities Erasmus Plus offers for student mobility in higher education.

-It is especially important that the rectorates of state universities finally begin to practice the rules for good financial management of European projects especially regarding the EU programmes Erasmus Plus and Horizont 2020- emphasizes Kolekeski. The National Agency for European Educational Programmes and Mobilities (NAEEM) was asked to respond to the question how many students annually participate in a student exchange and what is the maximum capacity for Macedonian students.

They explain that in accordance with the rules and procedure only the Universities signatory to Erasmus charters- Erasmus University charters have the right to apply in NAEPM where the selection of students for student mobility and student internships is carried at the home university and for the academic

year 2013-2014 the agency has signed contracts with Universities from Macedonia for a total of 228 mobilities.

Regarding the maximum capacity of Macedonian students there is not a limit for the possibilities for studying abroad with self-funding.

The only thing that needs to be done is to make the right choice of the country, faculty and to respect deadlines. Depending on the selected country, information for the necessary documents can be found on the web pages of embassies of the particular countries or on the web-page of the particular university students plan to enroll.

(The author is a student)

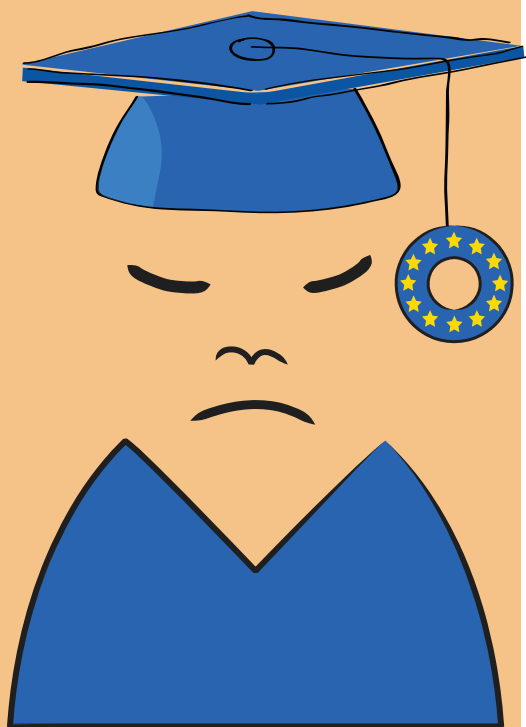
OVER FIVE MILLION EUROPEAN STUDENTS HAVE BEEN THROUGH "ERASMUS"

Over five million European students have been through the educational programmes for globalization and cultural exchange "Erasmus", formed in 1987, and have received scholarships and an opportunity for a short period of time to participate in an exchange at many of the European universities.

At the moment there are over 4000 institutions which participate in "Erasmus" in 33 countries included in the programme and the most popular destinations are Spain, Germany and France.

All the necessary information for students interested to be part of this programme can be found on the web page: www.ec.europa.eu/programmes/erasmus-plus, available in several languages.

As an entertaining guide and presentation for "Erasmus" at any given faculty, the Spanish film "Auberge Espaniol" has very often been pointed out as well as the documentary "Erasmus 24/7" and the book "Erasmus, here I come" available in electronic format. Useful links where you can find competitions for scholarships, internships, seminars or trainings at home and abroad are also :www.mon.gov.mk, www.mladiinfo.eu, www.magazine.danaucime.mk, www.fakulteti.mk/, www.na.org.mk/.



ALEX FERGUSON

I never pass a Big Issue vendor on the street

David McDonnell
Photo: Phil Noble

In an exclusive interview with The Big Issue, the famously short-tempered ex-Manchester United manager opens up about his life post-United, revealing he is relishing retirement and the challenges beyond football management. And he's also a big street paper fan.

For more than a quarter of a century his combustible presence and unique success made him the iconic face of English football. Now, 18 months on from retirement, Sir Alex Ferguson has opened up, claiming he has mellowed and no longer gets so worked up watching Manchester United.

The Old Trafford giants have endured a tough time since Ferguson ended his 26-and-a-half-year reign, with the David Moyes debacle and new boss Louis van Gaal still struggling to impose his philosophy.

But United's most successful boss and, arguably, the greatest manager the world has seen, says he has seen progress in his old side this season and believes they have played "lots of great football" under Van Gaal - particularly in the narrow 1-0 derby defeat to fellow UK club Manchester City.

In an exclusive interview, Ferguson opened up about his life post-United, revealing he is relishing retirement and the challenges beyond football management. "I really am [relishing it]," said the Scot. "And I can go and watch the team now without getting so worked up.

"I mean, we lost to City [earlier this month], but we did okay. Lots of great football. If it had been 11-a-side [United had Chris Smalling sent off before half-time], who knows?"

"I'm enjoying my football, I'm enjoying my family, my friends and I'm enjoying my retirement.

"I'm an ambassador for United and

I'm on the club's board of directors, so I still watch a lot of games, but I do miss the banter of the dressing room; the players, obviously, but also the backroom staff.

"All lovely people - cleaners, cooks, admin people, kit staff. Really decent, honest people. I don't see them as much now as I used to."

Ferguson may no longer be programmed to be up at dawn, as he was when he was in charge of United and the first person at the training ground every day, but his schedule is still relentless for a man who turned 73 last New Year's Eve. "Retired? Who's retired? I'm busier than ever," joked Ferguson, whose schedule included attending the Ryder Cup in his native Scotland - and delivering a pre-event pep-talk to the victorious European team - last September.

"It's perhaps my one concession to retirement - I don't need to get up quite so early, although I still wake early. I suppose retirement sees me just as busy, but the pressure's not as consistent as when I was managing United.

"I'm fine once I get going. Still use the gym - I was on the bike this morning. It's important to keep fit."

During his chat with The Big Issue, Ferguson said he has also embraced many charitable ventures since retiring and revealed his admiration for the magazine aimed at getting the homeless off the streets.

Retrieving a November copy of the Big Issue from a pile of correspondence on his desk at his Wilmslow offices, he said: "I never pass a Big Issue vendor on

the street, because these people aren't begging - they're trying to get back on their feet.

"Sometimes, if they've only got one or two copies left, I just give them a tenner and say hello to them because they'll want to sell their last copies and get some more cash but I do like to read the articles.

"What is it they say in here?" - he consults the magazine - "A hand

up, not a hand out?' Excellent!

"As a UNICEF Ambassador and through Manchester United's 13-year 'United for UNICEF Partnership' I've visited many projects. To hear how young people, especially orphans, suffer is always shattering. But I focus more on the UK these days.

"I'm committed to a lot of Manchester charities and to the development of Harmony Row Youth Club in Govan [where

Ferguson grew up].

"I'm the patron of the club and we've already raised £1.6million to build a state-of-the-art pitch. I have my own charity and I still do a lot of public speaking trying to raise money for good causes."

Since retiring, Ferguson has broadened his horizons, including lecturing students at America's famed Harvard Business School on his management and leadership techniques, with a rumoured book in the pipeline. "I'm loving it," he said. "I was over in Boston recently, talking to professors from the faculty, and I was making the point that inspiration is just as important as education.

"We talked a bit about how you pick the stars of the future and nurture them, something I've done all my life in football.

"I was very aware that the first time I clapped eyes on Paul Scholes, I thought, 'too small'. But that's when nurturing talent comes in. And you're rewarded hugely.

"It's a fantastic challenge but I'm speaking mostly about leadership and I'm comfortable doing that.

"I've always been blessed with a good memory, but Patrice Evra? There's a man with a brain. He could speak five languages and was a great help in the dressing room. Lovely guy. His father was a diplomat. It showed.

"Even better: See Diego Forlan? When he was with us he was also a great linguist and could speak about five languages fluently.

"Earlier this year, when he signed for Osaka, I was told that he prepared about a week in advance and then gave a five-minute interview to the media in Japanese! Now that's impressive." Ferguson has just updated his latest autobiography, adding two new chapters covering the first year of his retirement, and revealed how France boss Didier Deschamps made his players read it ahead of their World Cup campaign in Brazil last summer.

"Patrice phoned me and told me that as part of their preparation for the Brazil World Cup in June, Deschamps made the whole French squad read the book," said Ferguson.

"Evra said it was great as, five minutes after they started to read it, they've never slept better!"



GREEN REPUBLIC

THE AIR KEEPS US ALIVE BUT IT KILLS US AT THE SAME TIME


Valentina Stojanchevska

While the authorities are in a winter slumber a 21 year-old student daily, every hour, informs and warns the Macedonian public about the air they breathe. There is no doubt now that the air is polluted but what we are missing is the cure.

It has been few months since Macedonia has “won” the title of a country with most polluted air in Europe and the latest analysis and comparisons with other countries point to the fact that we have grabbed hold of it and will not give it away to anyone. As paradoxical as it may sound air which is harmful to our life still keeps us alive. Unfortunately we do not have another one. For now citizens’ only allies are the wind and the snow which purify it from time to time. In order not to be left to the mercy of the elements several thousands of citizens have raised their voice against pollution, yet the others such as the state seem to be in winter slumber. A range of activities and measures were announced, measurement stations were set up, yet the quality of the air we breathe still shows that we haven’t moved an inch. Obviously things cannot change overnight, yet it is clear that change has to begin somewhere.

A STUDENT RAISES AWARENESS FOR THE POLLUTED AIR

One of the first steps, of course is informing the public. A month ago, accidentally, but until now very successfully, the 21 year – old student Gorjan Jovanovski from FINKI set off on such mission to raise the awareness. Searching for information on how polluted our air is he realized that those published by the authorities are represented very obscurely and confusingly. As a result, he created his own Android app “Moj Vozduh” which in a simple and understandable manner reports on the quality of air in few Macedonian towns. Unlike the results presented from the Ministry of Environment, which are very often shown in a confusing manner, the app “Moj Vozduh” provides clean and simple view of the polluted air we breathe. -I got the idea when I tried to inform myself about pollution




on the web page of the Ministry of Environment and I realized that getting exact data was very difficult, especially on a mobile device. Because these data was available through the programme Open Data I decided to create an app for me which will show it. Few days later I decided to publish it for everyone, hoping that it will at least raise a little bit awareness among people about to what degree we pollute the air we breathe daily and in less than a month there are more than 9000 users who are being informed through it- says the student Gorjan Jovanovski for "Face to Face".

He points out that "My Air" has a goal to simplify the access to measurements and with the aid of visual indicators, explained notions and suggestions to make citizens think whether to use the car, bike or public transport when they want to go out.

This app uses data from 17

measurement stations located throughout Macedonia. The data is refreshed every hour and alongside the numbers which show the pollution there is a detailed explanation on what affects them and what is the allowed level.

The app shows the reasons for the pollution and informs the citizens on the measures they can take in case of extreme air pollution. For example, at the time this text was written when we were checking the air in Tetovo, the data showed a number of 169 mg/m³ PM₁₀ particles in the air and the allowed limit is 50. After this there is a recommendation all citizens to avoid staying in open air places and young children, pregnant women and the elderly are recommended not to go out unless necessary. For all of those who do not own and Android device "My Air" has its own web version.



Our interlocutor adds that his app perhaps will not clean the air, but for now, at least, he knows what he is breathing. He points out that his peers should be more active and fight for a cleaner environment.

-Of course I believe that the young should take up the initiative for protecting the air. Skopje has an unfavourable position where there is rarely wind, thus, it is up to us to deal with pollution. Using bicycles and public transport helps a lot to the end goal, as well as right wood heating in households, for which the young can educate the elderly- states Jovanovski, who alongside his studies, for five years he works with programming professionally.

What you can see daily on the app "My Air" recently was presented by the World Bank, and with new shocking results came out the web-site Numbeo, according to which the capital of Macedonia is at the top of the most polluted

European cities. According to the data of this web-page, which collects data on cities in different categories, Skopje is the European champion in pollution, "thanks" to the heavy industry. Skopje is followed by Moscow, Kiev, Torino and Tirana.

Despite the capital, the situation is alarming in Tetovo as well. The question is in the air whether this town will suffer the fate of Veles where the pollution for years took its toll on the people's health. The alarm was set off by several obstetricians from Tetovo who pointed out that the number of miscarriages and pregnancies ending with stillborns has risen in their municipality. The MP of DPA Meral Ferati, talked about the detrimental effects of the air on people's health.

-The air pollution is in alarming range and causes increase of the number of lung and cardiovascular diseases. We appeal one more time for measures to be taken immediately to put an end to this

massive poisoning in Tetovo and its surroundings which resemble a gas chamber- stated Ferati in the Assembly.

The Public Health Institute recently published an analysis which shows that in Tetovo there is an upward trend of circulatory and respiratory diseases. Therefore, if in 2011 there were 230.000 check-ups in the infirmaries and clinics due to cardiovascular and respiratory diseases in 2013 this number has risen to 340.000 check-ups. One of the more voiced activists for healthier environment is also Nenad Kocik, a doctor and activist in the environmental association "Vila Zora".

-In accordance with the Constitution of Republic of Macedonia the citizens have the right to live in a healthy and clean environment. The responsible institutions have an obligation or even better said, are paid to provide healthy and clean environment in Skopje, Veles, Tetovo, Bitola, Strumica...the whole Macedonia. Anyone can direct us to Karadzica, Jakupica or Baba, but as citizens of this country we have the right and responsibility to fight for a healthy and clean environment, for all the people in the country- states Kocik. He has no doubt that the air pollution, soil pollution and water pollution are related to the occurrence of miscarriages. When the examinations were carried out in Veles and increase in miscarriages was proven with both people and animals. In most cases this was related to the increased concentration of lead in the placenta of the mothers, however, the other air pollutants as well as soil and water pollutants are no less harmful. Even the last analysis that were carried out in Veles by the EU have shown that there has

been an increase of miscarriages and congenital malformations with women whose pregnancy was lead through the hospital in Veles- reminds and warns Kocik.

THE SOIL IN VELES STILL RICH WITH HEAVY METALS

Although people of Veles came out victors from the battle they fought with the smelter factory, still few years on they do not live in clean and healthy environment. On the contrary, the results from the soil analysis are terrifying. The team of professors: Zlatko Panchevski, Trajche Staflov and Katerina Bacheva from the Institute of Chemistry have conducted a professional research "Distribution of heavy metals in some of the vegetables produced near the smelting factory for lead and zinc". The research has shown that people who live around the now dead smelting factory breathe an air which is more than 10 times more polluted than the allowed and eat vegetables with presence of heavy metals. In other words, samples have shown that there aren't vegetables without high concentration of heavy metals. The smelting factory is history but pollution unfortunately isn't. Therefore, the non-governmental organization "Green Power" has announced that they will seek justice at the Human Rights Court in Strasbourg, because no one has taken responsibility for the numerous ruined human destinies. The environmental organizations are unanimous that this crushing data, as well as the findings from the World Bank, according to which the hard particles are responsible for more than 1350

deaths yearly should awake us. Therefore, they came out with recommendations and demands from the responsible institutions warning them not to compensate for the industrial pollutants and their environmental responsibilities. They have also offered several solutions, that is to say, they have recommended to close the central city zone for cars, to limit the use of cars (ban on cars with EURO 1, 2 and 3 standard), then they suggest public transport to be free of charge and to temporary ban the use of office vehicles.

The Ministry of Environment is asked to carry out control of the industrial capacities, the Ministry of Internal Affairs to increase the control of technical accuracy of the vehicles in traffic and the Ministry of Health to publish a list of free medicines for respiratory diseases targeted for vulnerable groups. It is demanded of all public institutions to ban the use of office vehicles. As systematic decisions it is recommended to preserve and increase the city's greenery and to increase the promotion of the bicycle as a transport vehicle because according to the European Cycling Federation a cyclist who passes 8km a day 4 days in the week, saves 380i of petrol and 750kg of carbon dioxide on yearly basis.

Whether any of these demands and suggestions will be accepted by the authorities it remains to be seen. Until then the won title will remind us of our great defeat. Because we started with the data that Skopje is the most polluted city in Europe, let's end with another set "record". Last year on 15 December a record pollution was measured from 538mg/m³ of PM10 particles in the air, or almost 11 times more than the allowed amount.

GREEN REPUBLIC

"GOOD LAND" FOR GOOD FOOD

Biljana Filipovska

The first cooperative for organic food in Macedonia has been formed. Its focus is not only to fulfill its practical purpose of existence – supply of organic produce, but also the membership in this cooperative is a direct way of expressing criticism towards the current dominant manner of growing food.

The necessity to hold in hand organic produce from local producers whom you will personally meet, the awareness of consuming this food and the necessity of information exchange in this direction has created an informal cooperative of consumers in Skopje under the roof of the Autonomous Cultural and Social Centre (ACSC). These associations are nothing new in the world, and the benefits of them have already been felt in Japan but also in Europe and Canada. The not-for-profit organization "Good land" has gathered in one place the producers and the buyers, and some of the members of the organization already realize actions and voluntary work with producers. The prices and the time of delivery of organic produce are a matter of agreement

and the socializing and sharing of information between both sides is a joint pleasure which no market can offer.

These alternative models of networking of consumers with producers derive from the need to give sustainable answers and solutions to the problems with which the world faces such as the excessive pollution from agriculture and transport of produce, alienation and the complete divide between the food consumers and food producers (a relationship without trust), the increased number of overweight people and at the same time the increase of famine world wide...

The conventional agriculture results in irreversible pollution and dying out of the soil as well as in pollution of underground waters, lost interpersonal relations and creation of a greater distance between the consumer and the producer, filled with marketing and plenty of pesticides. The transport also contributes to the pollution

and facts show that Macedonia imports produce that it has in large quantities or has a very favourable climate for their production. At the same time inequalities are created as well where the big ones dominate and pollute while the small ones fail and cannot fight for their survival.

In the developed countries these problems are publicly discussed, as well as what is the most sustainable systematic and long-term solution and the question is being posed loudly –how to leave our grandchildren healthy heritage?

The so called alternative models of trade as a response to these problems started to define themselves through a self-initiative back in the 1970's and Japan is the leader here and after 1980's they started developing in Europe, Canada and as of recently in the Balkans. Their focus is not only to fulfill their practical purpose for existence such as the procurement of organic produce, but the membership in these association is a direct way of expressing criticism to the current dominant manner of growing food.

One of the main principles of the alternative models for food procurement is that the product enables a direct link between the consumer and the person who produced the food and with it the land which has grown the product.

In different countries these initiatives have a different names and can have small differences in the manner of organization

but the system of values is everywhere similar or equal. The cooperatives (as they are called in the west) are this type of groups of citizens joined either formally or informally. The members of the cooperative are also its owners and with the right to vote which they receive through a one-time lump sum investment which is fully reimbursed if a member decides to leave. Thus each member has a direct influence to the way the activities are managed in the cooperative. If profit is made with the work of the cooperative it is used in accordance with the statute. In Macedonia payment of the sum is defined in the statute of the cooperative, and every member with the right to vote is an owner.

The cooperatives can be small with 50 members and there are also those which employ tens of thousands such as “Mondragon” in Spain or “John Lewis Partnership” in England. If it is registered, it is subject to the laws on trade companies, whereas the informal groups of citizens function completely voluntary and on non-profit basis. In the pricing policy the creation of prices is fair and accepted by both sides (producer and consumer). The structure of management in both cases is horizontal and the decisions are adopted transparently and with members' participation. The sociocratic principle is

in a way a consensus, there is an argument supported discussion until everybody can “live with the decision, one can volunteer at the farms according to the desire of its members and a relation of agreement and trust with the producer is being created and the food no longer represents a need but also coming closer to nature. On the other hand the process of production is seen from the opposite angle and it is respected more. Regarding the increase of sustainability with their functioning as well as improving the ecological footprint, the cooperatives lean towards full exclusion of the packaging material, especially plastic and they aim towards full recycling and reusing of the material that has to be used and they also organize packaging gathering activities.

(The author is founder of the first cooperative for organic food in Macedonia “Good Land”) www.dobrazemja.org



EXCLUSIVE
GRAÇA MACHEL ON LIFE AFTER MANDELA

In Mandela I saw a friend that today I sincerely miss

Ferial Haffajee

Last December, Nelson Mandela died at the age of 95. Mandela was a global icon who guided South Africa from the shackles of apartheid to multi-racial democracy. In doing so, 'Madiba' became a symbol of peace and reconciliation who embodied the struggle for justice around the world. He was the first black president of South Africa and in 1993 won a Nobel Peace Prize for his achievements. Now, for the first time, his widow Graça Machel – a renowned human rights advocate - breaks her silence on Madiba's death and reflects on their relationship for The Big Issue South Africa.



The black is gone. The scarf and shawl, the widow's identity, is packed away. But her eyes, usually commanding and curious, remain sad. Graça Machel enters a room to capture it. She has a leader's tall, determined gait, similar to that of her late husband.

We meet at Johannesburg's Saxon Hotel, where she turns every eye. And although last Friday marked the end of her formal mourning, her sadness is still palpable. She is dressed like a stateswoman: a smart winter two-piece suit, heels and a pashmina, which she spreads over her legs as much for comfort as for warmth.

She speaks of Madiba in the present tense, in words and sentences that linger in the air like she is checking in with him. "[Madiba] is... a lot of things to me. He is that very good friend you feel you connect with even if you don't talk. It's not only because of what you say. Just looking into the eyes..."

And she breaks off.

Madiba died last year, aged 95. For the last two years of his life, he was often ill. Machel undertook a vigil of love, caring for him at their Houghton home, which was turned into a hospital, and also at the Pretoria Heart Hospital, where he spent 12 weeks last year.

What does she miss about the man she married at 53, when he was 80? "I miss sitting with him in the lounge. I miss feeding him. I'd be holding his hand with one hand and feeding him with the other," she says, imitating the gesture, honed through practice - an act of love and nurturing, not of nursing. "The communication and intimacy from that was so profound. When I stopped feeding him [when the elder statesman was fed intravenously], I felt 'how will I communicate with him?'" Soon after, Madiba was hospitalised.

"The way of communicating was different, but we always communicated. Even at hospital, Madiba would recognise my touch. Even in a deep sleep, if I touched him, he would know it was me. The

expression in his face would tell: he heard me; he hears me. I would say, 'Good morning. Did you sleep well? It's Monday, it's the third. It's Sunday the fifth.' I would tell him who called, who sent an SMS..." That was a year ago, when the Heart Hospital became the site of a national outpouring of love for Madiba. Machel kept a tally of the choirs, church and school groups that visited, and gave Madiba a running commentary. "I wanted him to keep contact with the outside world. It was important that he didn't withdraw into himself," she says.

TATA'S JOURNEY INTO NIGHT

Did Madiba understand?

"The doctors confirmed to us that the last thing that goes is the hearing. He would listen and I knew he heard. Sometimes he would try to open his eyes. I would sit there and read and hold his hand until I felt he was asleep. I slept in a small cubicle, but I was able to feel when something was wrong. I would jump up from bed and see why the machine was complaining," she says.

Machel will not confirm this, but she almost lived at the hospital. Her daughter, Josina, dropped off fresh clothes for her. "There were times [when] I would help him to calm down when he was agitated and I'd say 'Papa, Papa, please...' and he'd rest. The doctors knew I could calm him down."

Meanwhile, a debate raged over whether Madiba should be at Qunu, in the Pretoria hospital or in their Houghton home.

"The doctors said to me, 'You know, at this point in time you can take him to China. What's important for him is where you are.' They said where I am, he is fine. [They said] I shouldn't worry about the physical place."

A LOVE THAT KEPT THEM YOUNG

Madiba and Machel made their relationship public in Paris while on a state visit, where they sneaked around with the aid of South Africa's then ambassador, Barbara Masekela.

Earlier this year, Jan-Jan Joubert revealed a delightful anecdote in the Sunday Times: on a rendezvous at the river-bank retreat in Mpumalanga of billionaire Johann Rupert, Machel arrived late at the bush airport. It was closed, but that didn't deter them. Machel climbed the airport fence. For a moment, there is joy in the air as Machel remembers and giggles.

"Even for myself, it was revealing. Age doesn't have anything to do with falling in love... Madiba was about to turn 80; I was in my early 50s. But we became like adolescents. You appreciate the voice, the touch, the being together. "All along our life we'd walk hand in hand. It was something automatic. We would get out of the car... and the first thing Madiba wanted was my hand. That's what I miss."

Photos of the pair reveal their hands glued together, and often their lips too.

"Let me tell you, Madiba was more gorgeous when he was older than when he was younger. I'd look at his photographs and say, 'You are much handsomer now.' He was a tower. I mean, I'm not a short person, but next to him I had to look up. He was a tower."

Machel met Madiba at a lonely

time in his life. "He was separated [from Winnie Madikizela-Mandela], not yet divorced," she says. She speaks effusively about what he brought to her life. But what did she bring to his? She tries to squirm out of answering, saying I should have asked her husband. It's too late for that, I say. "It was about having someone who would restore dignity, that is what he would say: I restored dignity to him. "I don't think I should be talking about this. Madiba had felt rejected and just to be accepted again and to be valued and loved and cared for. The thing that was special with me was that for the first time Madiba would have a family life. A family life where there is predictability. "You can wake up in the morning, and you know the person is there. You can go to work and you say you will meet at lunch. And you know in the evening you will be together. In his first and second marriages, with his political activism, he could not give his wives that sense of normalcy in their lives." The couple would speak twice a day, or more, if they were travelling separately. Madiba would drop everything to fetch his wife from the airport, even if she was only hop-skipping to Maputo for the day.

GRAÇA MOVES ON

"Literally, it's the company I miss. It's his presence. Sometimes we'd be sitting in the lounge... he would be reading and I'd be doing my own thing. And we'd talk and talk and talk... and you feel that there's that connection." She laughs. "We didn't always agree, of course, but you'd know there are no no-go areas... You don't have to protect yourself. That's the friend I have in him and, to be honest, that's the friend I miss." She pauses, and repeats herself quietly. "That's the friend I miss..." Machel will now resume her slate of global roles - from her work with women and children to her role in the Elders, a UN group of leaders including Kofi Annan, Archbishop Emeritus Desmond Tutu and Richard Branson. She rules out running for president of Mozambique, a prediction that surfaces periodically. She will live in South

Africa and Mozambique - she is a citizen of both. She moved out of the Houghton house she shared with Madiba, because it held too many painful memories. She now lives elsewhere in Johannesburg. "The mourning has not ended. The grieving has not ended. What has ended is the formal mourning," says Machel. "The dressing, not talking in public, that you can't be away at night. The family and the Tembu elderly acknowledged that I work and it would be extremely difficult for me to be confined for a whole year, so they shortened it to six months." Throughout the interview, she speaks of "our family" - the

extended, troubled Mandela family. She will not talk about Madiba aide Zelda la Grange's book, *Good Morning, Mr Mandela*, which detailed family schisms and feuds.

La Grange wrote about how Machel was poorly treated by Madiba's eldest daughter, Makaziwe, who reportedly made Machel apply for accreditation to attend her husband's funeral. In the way of the schooled stateswoman, Machel says nothing of this, only that she is still reading the book and that, "It's Zelda's life, her journey, her experience and I respect that. "She [and I] are on easier ground talking about love."





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СПОДЕЛИ ДОЖИВУВАЊА

EVE ENSLER: ON CANCER AND RAPE IN THE CONGO

The cancer fight pushed me back in my body

Rosette Royale



Eve Ensler is an American playwright, author and activist who's famous across the world for her play, *The Vagina Monologues*. Ahead of a recent visit to America, she spoke to Real Change in Seattle about her new book – *In the Body of the World: A Memoir* – which documents recent momentous changes in her life. These include visiting the Congo in Africa to help female victims of rape and torture and a personal cancer diagnosis that profoundly shocked her.

Situated in the heart of sub-Saharan Africa, the Democratic Republic of the Congo (DRC) is a country that's both green and red at the same time. The equatorial climate allows palm trees to flourish and provides lush habitat for the world's only wild population of bonobos, primates that are some of human's closest evolutionary relatives. The soil contains untapped raw minerals estimated to be worth more than \$25 trillion, making it a country that, along with having some of the world's poorest people, possess some of the globe's most valuable mineral resources. The DRC is also the focal point for what's often referred to as the 'African World War', a conflict involving nine African nations that began in 1998. Violence and disease stemming from that conflict have resulted in the deaths of more than 5 million people. The Journal of American Medical Associations reported in 2010 that 40 percent of women in the Eastern Congo have experienced rape and/or sexual violence. The UN says the figure is the highest percentage in the world.

On one level, such troubling statistics motivated Tony-winning playwright Eve Ensler to travel there. Famous for her seminal work *"The Vagina Monologues,"* Ensler travelled to the war-ravaged country because, she told the New York Times in February 2011, she wanted to help "build an army of women." Not that she planned to arm them with rifles and bullets. Instead, she helped Congolese women build a center where they could gain skills to become leaders in their communities. The center is called City of Joy.

While the completion of the center filled Ensler with joy, her time assisting women in DRC coincided with a personal crisis: She was diagnosed with uterine cancer. She underwent months of treatment in the United States, including a nine-hour surgery in which surgeons removed numerous organs, including her uterus, ovaries, cervix

and part of her vagina. She balances events in DRC with the illness in her body in her newest book, *"In the Body of the World: A Memoir"* (Metropolitan, \$25). It's a mesmerizing story. Ensler tells it in a voice that's both sharp and soothing. She writes openly about how cancer affected her own body, including her ileostomy, a surgery that brought part of the small intestine outside of the skin's surface. Intestinal waste was collected in a bag outside of her body. Ensler talked to Real Change in Seattle, USA, ahead of a recent visit she made to the city.

What caused you to go the Democratic Republic of the Congo?

I went about seven years ago at the request of Dr. Denis Mukwege, who is the director of the Panzi Hospital and is a doctor and a surgeon and a gynecologist, who has been working in the middle of the war for the last 14 years, sewing up women as fast as the militias are ripping them apart. I had interviewed him at the bequest of the UN and was completely overwhelmed by his nobility and devotion and brilliance. And he asked if I would come to help with their efforts. So that's what brought me there.

Your book is called "In the Body of the World," and it draws up a lot of ideas. One is about landscape. So how would describe the Congo?

Well, I would say the Congo, particularly Eastern Congo and [the Congolese city] Bukavu, is one of the most beautiful places I've ever been. It's some of the most fertile, green, gorgeous land, and Lake Kivu is this stunning body of water, which can be kind of sea blue or sky blue, or it can turn black, depending up on the day. A friend of mine once said, "It's hell in paradise." Earth and birds and fruit and mangoes and avocados and bananas: life. And then this incredible violence being enacted both on the landscape and on the minds and on the bodies of people, particularly the women.

**Here's where questions get difficult.
How did you see that violence
manifest in and on the women there?**

Because we've now built this amazing place with them called City of Joy, I've heard many, many stories of women who have been violated in the most atrocious ways I've ever heard, during this 13-year-old war over minerals of the Congo. Over minerals [and ores] like coltan - which go into our cell phones and our PlayStations and computers - and copper and gold, which get pillaged by the West and China and the world. Those minerals are taken [when] militias go into the villages where the mines are, and they rape the women and have fathers rape their daughters and sons rape their mothers, and everyone be raped in general. They destroy the families, they're fractured. And the families flee, and the militias move in and they take over the mines with the multinational corporations. So we're seeing the coming together of the worst forces of the world - this capitalist greed, and sexism and racism and colonialism - which is destroying the indigenous Congolese. I think that's the landscape: You see this beautiful world and country and earth, and then you see that the majority of the people can't even live in the bush anymore, the forest, because the forest has become the most dangerous. So Bukavu: It used to have 50,000 people, and now there's a million people. And no jobs and no work and no structures and no streets and police and no law and no water and no electricity. Everyone's there just because they're terrified to live in the bush where all the raping and murders occur. What I'm interested in is how many of us - and I think it's men and women - leave our bodies, based upon trauma and pain. For me I've tried so many ways to get back in: whether it was, at a young age, drugs or promiscuous sex and then eating disorders and then performance art. And then, eventually, "The Vagina Monologues" and talking to as many women as I could about their bodies, and discovering why this worldwide epidemic of violence is at the root of why so many people have left their

bodies. The Congo was the further extension and the most extreme manifestation of that violence. And then getting cancer, which was the thing that, oddly and ironically, landed me smack in my body. I just became body. So that's really what I'm interested in now: How we get back into our bodies, which is the connective pathway to our connection to the earth, to each other, to everything that matters. I think this global disassociation, this global bifurcation is what is at the root of allowing so much to continue, whether it's insane poverty or economic injustice or racial injustice or climate change. We're not feeling what's going on. And I think the question is: How do we get back into our bodies so we feel it?

**Could you talk about how you
discovered that you had cancer, and
the journey that that took you on?**

Well, what I talk about in the book, in the chapter called "Somnolence," is that there were signs about my cancer long before

I ever did anything about it. I've talked to so many people who have had cancer or sicknesses, and they see things are wrong and they don't do anything - in the same way we understand that climate change is happening and we're not doing anything, and the same way we see that people are starving all around us and we're not doing anything. I think the signs got [to be] too much: There was blood coming from my body, and it was like I had to deal with it. And by then it was late, really late. I had a huge tumor about the size of a mango inside me. So I think it was profoundly shocking and yet that feeling when you know something's wrong, so it's not completely shocking. It's like when someone just rips off the veil of denial.

**You write and talk so honestly about
it. How difficult was it to tell your
truth about your illness?**

Well, I think when you get cancer, it's a process of coming to terms with what's happening. I think



In the past decade Eve Ensler helped in the construction of a center for women rights in Congo. 40% of the women are victims of sexual assault.

you're brain just can't believe it. The minute someone says to you, "You have cancer," it's like someone has just said, "You're dead." And then you have to begin to gather the forces. I had just never read a book where anyone had told me really what it was like to have cancer, and I wanted that book. I wanted someone telling me what it was like to have [ileostomy] bags and what it was like to lose control or what it was like to have an infection where you became the Gulf of Mexico. That was the book I needed, so I guess that was the book I wrote. So much of what happened to me was coming into my body, into the body of the world. So when I had [an] infection, it was happening simultaneously with the Gulf [oil] spill, and literally there were days where I felt like I had oil in me and pelicans dying in me. It was both horrifying and amazing, to just begin to see the metaphor and see the connective tissue that runs through one's



body into the world.

Is there a way for other people to connect deeper into the body of the world without having an illness?

I hope so, and that's what the book is saying - right? - where we don't need to get to a point where we destroy the earth before we appreciate it, or have our bodies die before we honor them. I think there are many pathways into your body and many pathways into connection. A lot of it has to do with being awake here and being willing to come out of the so mnolence. Hopefully the death of my somnolence will help other people to wake up. That would be the idea.

There's a person in this book: Dr. Handsome. You mentioned that it only takes one sentence from a doctor to give patients dignity. Could you expound upon that?

In the course of my treatment, I had really good care and not good care. And really good care has to do with the doctor or the nurses or whoever actually seeing you as a human being. So often people just get into kind of doing their job and doing it effectively and looking at your body as if it were an objective thing. For me, that moment with that doctor was such a profound moment, because I was in a state of utter humiliation, utter terror, utter nausea, lying on this table, not knowing where the cancer was, knowing I had this tumor inside my body, inside my colon: inside me. I was just utterly crushed. And in walks this gorgeous doctor, and I think, OK, this could be the end of the world. His walking around that table and acknowledging me and acknowledging my work and acknowledging my being. Everything changed for me. It all felt like I could handle it, and I could go through it because he had made a connection with my heart. He had connected me with his heart. It wasn't this cold medical process: It was this journey we were going to go on together. I think that makes all the difference.

At one point in the book, you mention you were a group leader in a homeless shelter. What do you recall of some of the trauma the women experienced?

I worked in a homeless shelter for around eight years, and it was a profound time of my life. For me, many things stand out. One is

how many women I met who had been violated or suffered insane violence, which was a huge reason that their trajectory had gone downward. But there was also the incredible unwillingness of people, who were outside the homeless community, to not understand that [homeless people] were on a continuum of poverty and exile through an economic system that is progressively making more and more people poor. And it was fascinating to me how people distanced themselves from homeless people, because some [people who aren't homeless] know it's a slippery slope, because there is no real system of economic justice or containment, so any of us can fall off at any moment. So people don't want to be near homeless people because they feel they'll catch it. That was what I was struck with over and over and over: How homeless people become contaminated and isolated and a thing, rather than just someone who lost their home and don't have money, for whatever reason. Whether it be economic investment or losing work or a tragedy. It taught me a lot about this whole capitalist structure, and how easy it is for people to lose their way.

How is City of Joy doing?

Wonderfully. I was just there for the month of February, and it is glorious. The bougainvillea is thick, and the roses are higher than me, and the women are unbelievable. They're just miracles. They come, and they're destroyed, they have nightmares and diseases and they have dread, they have despair. And they become the most beautiful, empowered, inspired, joyous beings, who are off to lift up the communities. I don't know. I don't think I've ever been as proud or inspired by anything.

How's your health now?

Today I have three years clean [of cancer], and I'm alive. And every day that I'm alive is a gift. A huge gift. It's absurd that I'm alive, and I get it, and I get that I have the privilege of having health insurance, which afforded me treatments and medical care that 99 percent of the planet aren't afforded. So I try to do as much as I can every day in service as my debt of gratitude.

Pece, Marta and Viktorija
"Band"



Because of the FOP disease Viktorija's muscles turn into bones and now she is in a fixed position in her electronic wheelchair. Strumpell's syndrome, on the other hand causes muscle atrophy, and thus movement becomes more and more difficult for Marta. These lovely girls with typical teenage interests love music, are constantly on Facebook and Viber and enjoyed the the make-up and singing for the joint melodious photo with Pece.

Vesna Aleksovska and Tanja Kokey
"Distance"



A slightly stronger embrace was enough reason for a broken bone or a bruise on her body. The lack of enzyme brings to the accumulation of gaucher cells in the organs and in the bone marrow. Because of that the organs increase in size and the bones are prone to fracturing. Bruises, fatigue, faintness are all daily possible symptoms of the people with untreated Gaucher's disease. Vesna has been receiving therapy for five years now, her state is stable now and she leads a normal life.

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Rebeka and Markijan

