
Andrej E. Skubic

Hura, Nosferatu!

Hurrah, Nosferatu!



NETA – Nova evropska teatarska akcija / New European Theatre Action
Slovensko narodno gledališče Nova Gorica / Slovene National Theatre Nova Gorica
Slovensko mladinsko gledališče Ljubljana / Mladinsko Theatre Ljubljana
Kulturno društvo B-51 / B-51 Cultural Society (EX PONTO)

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Koprodukcija / Co-production

NETA – Nova evropska teatarska akcija /
NETA – New European Theatre Action
Premiera 29. avgusta / Premiere 29 August
2015, Narodno gledališče I. L. Caragiale
Bukarešta / National Theatre I. L. Caragiale
Bucharest (Festival NETA / NETA Festival)

Slovensko narodno gledališče Nova Gorica
/ Slovene National Theatre Nova Gorica,
sezona / season 2015/2016, uprizoritev /
Production 1
Premiera 16. septembra / Premiere 16 Sep-
tember 2015, mali oder / small stage SNG
Nova Gorica

Slovensko mladinsko gledališče Ljubljana /
Mladinsko Theatre Ljubljana, sezona / Sea-
son 2015/2016, uprizoritev / Production 1
Premiera 26. septembra / Premiere 26 Sep-
tember 2015, zgornja dvorana / upper hall
SMG Ljubljana

Kulturno društvo B-51 (EX PONTO) / B-51
Cultural Society (EX PONTO)

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2007

Krstna uprizoritev / First Staging

Režiserka / Director **Simona Semenič**
Dramaturginja / Dramaturge **Simona Hamer**
Lektor / Language Consultant **Srečko Fišer**
Scenografinja in oblikovalka svetlobe /
Set and Light Designer **Petra Veber**
Kostumografinja / Costume Designer **Amanda Kapič**
Avtor glasbe / Composer **Boštjan Narat**
Asistentka režiserke in lektorja / Assistant to Director and Language
Consultant **Laura Brataševec**

Vodja predstave / Stage Manager **Simon Kovačič**, šepetalka / Prompter **Arjana Rogelja**.

Tehnični vodja / Technical Director **Aleksander Blažica**, tonski in video mojstri / Sound and Video Masters
Vladimir Hmeljak, Majin Maraž in / and **Stojan Nemec**, lučni mojstri / Light Masters **Samo Oblokar**
(vodja / Head), **Marko Polanc** in / and **Renato Stergulg**, rekviziterja / Property Masters
Damijan Klanjšček in / and **Jožko Markič**, frizerke in maskerke / Hair and Make-Up Stylists **Katarina Božič**,
Hermína Kokaš in / and **Ana Lazovski**, garderoberki / Wardrobe Mistresses **Jana Jakopič** in / and
Mojca Makarovič, odrski mojster / Stage Foreman **Staško Marinič**, odrski tehniki / Stage Technicians
Dean Petrovič, Bogdan Repič in / and **Dominik Špacapan**, vrviščarja / Flymen **Damir Ipavec** in
Ambrož Jakopič, odrski delavec / Stage Hand **Jurij Modic**, šivilje / Dressmakers **Nevenka Tomašević**
(vodja / Head), **Marinka Colja** in **Tatjana Kolenc**, mizarja / Carpenters **Darko Fišer** (vodja / Head),
Marko Ipavec in / and **Marko Mladovan**.

Pri uprizoritvi sodelujeta tudi tehnični ekipi Slovenskega mladinskega gledališča Ljubljana in Kulturnega društva B-51. / Additional technical teams Mladinsko Theatre Ljubljana and B-51 Cultural Society (EX PONTO).

Predstava nima odmora. / The performance has no interval.

Aleš **Blaž Valič**
Nataša **Maja Nemec**
Vida **Arna Hadžialjević**
Luka **Boštjan Narat** k. g.
Mama Marija / Mother Marija **Damjana Černe**

V predstavi so uporabljeni odlomki pesmi Lane Skubic / The performance uses parts of poems by Lana Skubic.

Zahvaljujemo se Andreju in Klari Skubic, dr. Igorju M. Ravniku in dr. Vali Tretnjak Glavič za vso pomoč in informacije. / Special thanks for help and information to Andrej and Klara Skubic, dr. Igor M. Ravnik and dr. Vali Tretnjak Glavič.



Simona Semenič Foto / Photo Nada Žgank



Andrej E. Skubic Foto / Photo Timohir Pinter

S politično korektnostjo v resnih življenjskih preizkušnjah ne prideš nikamor

Intervju z Andrejem E. Skubicem in Simono Semenič

Nagrada Prešernovega sklada za roman *Koliko si moja?* (Beletrina, 2011), kresnik za romaneskni prvenec *Grenki med* (DZS, 1999), *Koliko si moja?* (Beletrina, 2011) in *Samo pridi domov* (Modrijan, 2014), zmaga na natečaju Cankarjeve založbe za najboljši sodobni roman z delom *Popkorn* (Cankarjeva založba, 2006), Župančičeva nagrada za roman *Popkorn* (2007) in Sovretova nagrada za prevoda *Čitanke Gerturde Stein* in roman *Kako pozno, pozno je bilo* Jamesa Kelmana. Šest romanov, ena zbirka kratkih zgodb, trije dramski teksti, znanstvena monografija *Obrazi jezika* (Beletrina, 2005), nešteto prevodov ... je povzetek ključnih mejnikov profesionalne poti pisatelja, prevajalca in dramatika Andreja E. Skubica.

Grumova nagrada za dramske tekste *5fantkov.si* (2009), *24ur* (2010) in *Sedem kuharic, štirje soldati in tri sofije* (2015),

nagrajene uprizoritve v skoraj vseh slovenskih gledališčih, odmevne uprizoritve v tujini, avtorski projekti (*Jaz, žrtev*, 2007, *43 srečnih koncev*, 2010, *Drugič*, 2014), vodenje Pregleja – laboratorija dramskega pisanja in številnih (mednarodnih) delavnic dramskega pisanja, vodenje gledališča Glej, dramaturgije, producentsko delo ... je povzetek ključnih mejnikov profesionalne poti dramatičarke, dramaturginje in performerke Simone Semenič.

Hura, Nosferatu! (2007) je njuno prvo poklicno sodelovanje. Vanj vstopata v na videz netipičnih vlogah – kot avtor dramskega besedila in režiserka.

Andrej, poznamo te kot večkrat nagrajenega pisatelja in prevajalca, z dramatikom pa si se do sedaj ukvarjal trikrat; *Neskončni šteti dnevi* (SNG Nova Gorica, 2009), *Hura, Nosferatu!* (2007) – ki ti je leta 2009 prinesel nominacijo za Grumovo nagrado – in *Pavla nad prepadom* (Slovensko mladinsko gledališče, 2014). Kje vidiš ključne razlike med prozo in dramatikom in ali to vpliva na tvoj proces pisanja? Ti dejstvo, da je drama nekakšen »polizdelek«, ki zahteva posrednika, preden pride do naslovnika, pomeni poseben izziv?

Andrej: Seveda sem imel zmeraj rad teater, vendar mi je bil tako fascinantno oddaljen, da nisem nikoli resno razmišljal, da bi pisal zanj. Proza, tisto ždenje za računalnikom v intimi sobe, mi je bilo dosti bliže kot druženje z igralci, režiserji, dramaturgi, scenografi ... Potem pa me je dogajanje ob uprizoritvi *Fužinskega bluza*, ki je na pobudo

Janeza Pipana doživel gledališki krst v SNG Drama Ljubljana (2005), tako vznemirilo, da sem hotel napisati čisto svoj tekst. Čisto banalno: v romanu napišem neko sanjarijo lezbične scene in potem SNG Drama najame dve odlični igralki, Aleksandro Balmazović in Sašo Mihelčič, da to uprizorita? Pa saj boljše ne more biti! Ampak gotovo znam napisati tudi kaj boljšega. Zato sem moral iti naprej; kasneje so *Neskončni šteti dnevi* nastali kot predelava kratke zgodbe v dramo. Ja, prepuščanje »polizdelka« drugim ljudem, ki jim moraš zaupati, je poseben izziv, ampak je bilo doslej, hvala bogu, vsakič zelo v redu ... Sploh uprizoritev *Pavle nad prepadom* me je tako podrla – pa mislim tako, pozitivno –, da sem imel občutek, kot da to sploh ni moj tekst, ampak da gledam nekaj čisto novega. Šele ko sem prevajal podnapise v angleščino, sem

videl, da niso ničesar spremenili, le manj kot četrtnino so izrezali ... Prispevek celotne ekipe je bil tako velik, da je predstava precej presegla tekst. V tem se mi zdi čar pisanja za teater.

Simona, poznamo te kot uspešno in večkrat nagrajeno dramatičarko in čeprav imaš za sabo cel kup predstav, ki si jih avtorsko (so)zasnovala (*Polna pest praznih rok*, 2001, *Solo brez talona*, 2003, *SheSaid*, 2005, *Iz Principa*, 2009, *Kdo je naslednji?*, 2011 ...) in marsikatero tudi sama izvedla (*Jaz, žrtev*, *Drugič ...*), te v vlogi režiserke redko srečamo. Kako je prišlo do sodelovanja? Kaj te je pritegnilo?

Simona: Sicer so mi že večkrat predlagali, da bi poskusila režirati svoje tekste, ampak



se nekako ne želim postaviti v vlogo, ki bi od mene zahtevala, da interpretiram samo sebe. Glede na to, da poznam gledališki proces, bi me bilo namreč strah trenutkov, ko pred igralci ne bi zmogla zagovarjati ali utemeljevati svojega teksta in bi bila negotovost Simone – dramatičarke prej minus kot plus.

Moje sodelovanje pri *Hura, Nosferatu!* se je začelo z Andrejevim mailom. Pisal mi je, če bi me zanimalo režirati njegov tekst, in moja prva reakcija je bila: ne, ne, ne, nikakor ... nakar sem vse skupaj prespala in premislila ter rekla: zakaj pa ne. Kar me je še posebej pritegnilo pri projektu, je seveda lastna izkušnja z epilepsijo in izziv, da se ukvarjam s to temo v perspektivi nekoga drugega. Andrejevo življenje je zaznamovano z boleznijo na drugačen način kot moje – poleg tega ima njegova hči sindrom Dravet, torej veliko hujšo obliko epilepsije kot jaz. In bolj kot sem razmišljala o teh stvareh, bolj sem se veselila možnosti pogleda z drugega zornega kota.

Andrej, *Hura, Nosferatu!* je izrazito osebna drama. Lahko poveš kaj o genezi teksta? Kako da si se odločil za dramsko in ne romaneskno formo?

Andrej: Konec koncev so vse napisane zgodbe po svoje osebne, izhajaš iz doživetja, situacije ali dogodka, ki ti je segel do živega in hočeš z njim razčistiti. Zmeraj se razgaljaš. Seveda je bilo zame doživetje hčerke, ki se je prvih šest mesecev razvijala kot normalen dojenček, potem pa dobila najprej prve epileptične napade, kmalu zatem pa še diagnozo sindroma, ki je že v prognozi vključeval kognitivno prizadetost, neodzivnost na terapije, možnost psihoz in dokaj visoko smrtnost, najmočnejše

doživetje mojega življenja. Ob čem takem ti v glavi zbledijo vse ljubezenske travme, vsi družbeni škandali ali krivice. To ti seže do korenin in to je bilo treba prebaviti. Z ženo sva to prebavljala vsak dan sproti, po malem. Vendar je to izjemno težko ubesediti, imel sem zadržke, da bi pisal o tem. Prvič sem poskusil že v času, ko je katastrofična faza hčerine bolezni še trajala, v kratki zgodbi »*Nič hudega ni*« (Norišnica, 2004). Kajetan Kovič je nekoč zapisal: »dokler boli, ni jamb in ne trohej«. Tisto zgodbo sem napisal, ko smo s tem iz dneva v dan živeli, ko je še bolelo. Hči je imela srečo, to fazo bolezni je po nekaj težkih letih prestala še kar dobro. Nazadnje smo našli tudi dokaj uspešno kombinacijo zdravil, da je občutek neposredne vsakdanje ogroženosti popustil, čeprav so ostale razne druge težave. Mogoče je potem prišel čas za »jamb ali trohej«. Hotel sem napisati tekst o tistih občutkih, ko v ekstremno stresnih časih iščeš razne strategije preživetja. Z ženo sva to prenašala na sicer različen, po svoje pa tudi podoben način, tako da sva bila zelo uigran tim. Seveda so bili konflikti – nekateri so malo karikirano prikazani tudi v tekstu – ampak skupno točko sva našla v nekakšni strategiji črnega humorja, tudi samoironije, ki nama je pomagala ohranяти zdravo pamet. Hvala bogu, da sva se znašla skupaj – dva tako sorodna, ampak komplementarno različna človeka. Ta konflikt pa je bil vsekakor dramski, ne romaneskni. Hotel sem podobo razkola, njegovo nerazrešljivost; v romanu se ne bi mogel izogniti natančnim refleksijam, opisom, ki jih dejansko nisem zmožen spraviti skupaj na verodostojen način. Niti ne vem, če bi jih hotel brati. To stanje duha je mogoče prikazati samo s sliko, z uprizoritvijo.



O vsem drugem pa mora vsak gledalec razčistiti sam pri sebi.

Simona, ti si o svojih boleznih spregovorila v besednem solu *Jaz, žrtev* in v nadaljevanju *Drugič*. Blaž Lukan je pristop označil kot avtoreferencialno verbalizacijo teme, v obeh primerih pa je tekst zasnovan kot direktni nagovor publiki ali bralcu. V primerjavi z Andrejevim klasično dramskim načinom podajanja je to kar radikalen postopek.

Simona: Pri *Hura, Nosferatu!* sta me takoj pritegnila njegova iskrenost in dejstvo, da je na zelo neposreden način izpostavil sebe in celo svojo družino ter zelo odkrito spregovoril o njihovem vsakdanu. Prav ta iskrenost se mi zdi vredna občudovanja in mi je zelo blizu. Zato se mi tudi zdi tako

pomembno, da se tekst uprizori. Čeprav se bojim, da naša predstava oziroma naša interpretacija Andrejevega teksta ni točno takšna, kot bi si jo Andrej predstavljal in želel ...

***Hura, Nosferatu!* dvojnost, vpisano že v naslovu, razvija v dve vzporedni in prepletajoči se zgodbi; okvir predstavlja pisatelja Aleša, ki se skozi proces pisanja spopada s smrtjo hčerke z sindromom Dravet, medtem ko druga linija sestoji iz slik vsakdana družine otroka s posebnimi potrebami. Kje je bil tvoj primarni fokus?**

Andrej: Nisem hotel pisati družinske zgodbe otroka z malignim epileptičnim sindromom; v tej še vedno živim, čeprav je danes bolj umirjena kot pred šestimi leti. Hotel



sem napisati zgodbo o smrti, ki uniči družino, in o tem, kako jo nekdo prebavi ali pa ne.

Simona, kateri segment pa se je tebi zdelo ključno izpostaviti v uprizoritvi in zakaj?

Simona: V enem izmed mailov, ki sva si jih z Andrejem pošiljala, mi je – malo v šali, malo zares – napisal, da jaz nisem Vida in naj se ne postavljam v njeno vlogo. In kakor mi je kristalno jasno, da je Vidina anamneza drugačna od moje, se mi zdi njegov strah upravičen. Čeprav je očetov občutek krivde glavna tema, ki je Andreja zanimala, se mi je zdelo izjemno pomembno izpostaviti Vido; njeno voljo do življenja, njeno čistost, nedolžnost. In istočasno seveda tudi krivdo, ki je na tak ali drugačen način pravzaprav pri-

sotna v vseh nas – kriv si, ker si živ ... Jaz se počutim krivo, ker imam epilepsijo, saj so se zaradi tega moji starši zelo namučili, ker je bil moj brat v drugem planu in tako naprej. In ta krivda je tako odvečna komponenta naših življenj ... Jaz imam božjast; tako pač je, ampak ni treba, da se počutim krivo, ker je moji mami hudo zaradi tega, in obenem moja mama ni kriva, če mene vrže. Kako že reče Kurt Vonnegut: Tako gre to.

Ena izmed režijskih intervencij je tudi glasba, ki v uprizoritev vstopa preko lika Vidinega starejšega brata, Luke.

Simona: Lik Luke se mi je zdel ena izmed šibkejših točk drame, ker nekako izgineva skozi tekst; je, pa ga ni, potem se spet malo pojavi, pa ga spet ni ... Po mojem je z dra-

maturškega vidika njegova vloga ključna, saj edini jemlje Vido takšno, kot je; v tekstu celo reče: »Ona ni bolna, ona je ona!« in »Samo po svoje je fajn, da ima Vida Dravet sindrom. Pol je tako lepa in bela, pa se toliko crklja. Ona je nekaj posebnega.« Luka se uči igrati kitaro, s sošolci ima bend *Hura, Nosferatu!* in tako sem, v želji podpreti lik Luke in imeti v predstavi živo glasbo, prišla do zaključka, da je najboljša, če Luko odigra kar glasbenik naše predstave, Boštjan Narat.

Še en izstopajoči element sta dve pesmi Andrejeve hčerke Lane, ki sta vključeni v predstavo.

Simona: Na eno od začetnih vaj smo poleg dveh strokovnjakov s področja epilepsije in nevropsihologije, dr. Igorja M. Ravnika in dr. Vali Tretnjak Glavič, povabili tudi Andreja in njegovo ženo Klaro; takrat nam je Andrej povedal, da Lana piše pesmi in prozo. Poslal nam je dve in zdeli sta se nam tako lepi, popolni v vsebini in formi, da smo jih vsi – celotna ekipa – takoj hoteli vključiti v predstavo. Čisto instinktivno smo zelo hitro našli mesti v predstavi, kjer bi ju lahko uporabili. To je zame na konceptualnem nivoju pomenilo še dodatno okrepitev Vidinega lika in moje želje po predstavitvi njene lepote in volje do življenja. Ja, če je Aleš dobil odvetnico v Vidi, se je meni zdelo, da moram biti v tem procesu jaz Vidina odvetnica.

Drama odpira vrsto vprašanj; od stigmatizacije (otrok), reorganizacije družine in nerazumevanja, ki so ga deležni s strani družbe, kritike zdravstvenega sistema ... Andrej, si se med procesom pisanja tudi ti ukvarjal z vprašanjem »politične korektnosti«? Na vajah smo

namreč veliko govorili o tem, da ne želimo Vide prikazati zgolj kot bolnega otroka in želimo družino Petrač predstaviti v skladu z Natašino repliko: »Mi smo normalni, samo pravila moramo upoštevati.«

Andrej: Midva sva hčerko vsekakor ves čas doživljala kot bolnega otroka – ampak v smislu otroka, ki je potreben pomoči in verjetno nikoli ne bo mogel skrbeti sam zase. Hkrati pa njej nisva hotela dajati občutka, da je z njo karkoli narobe. Konec koncev za svoje napade niti ni vedela; če je pa že vedela, da smo mogoče malo prej hodili po parku, v naslednjem trenutku pa se je po epileptičnem statusu zbudila v bolnišnici, je bil to zanjo pač običajen dogodek. Ves čas naju je skrbelo, kako se bo soočila z ugotovitvijo, da je »drugačna«, in koliko bo zanjo to boleče. A smo se s tem le redko kdaj soočili. Vključena je namreč v posebno šolo, kjer so otroci zelo različnih sposobnosti in se ji zdi popolnoma samoumevno, da nekateri ljudje nekaj zmorejo, drugi pač ne. Zato ji je nekako razumljivo, da pri štirinajstih ne zna seštevati nad deset, čeprav njen sedemletni bratec zna, ampak kaj hočemo; še zmeraj sanjari, kako bo nekoč vozila avto in imela otroke, in ni potrebe, da bi ji te sanje razdirali. Normalna je v tem, da je srečna in žalostna, da je ljubeča in ljubljena, da se z njo zaradi obnašanja kdaj skregamo kot z vsako najstnico. Vsekakor je zase normalna tako, kot sem zase normalen jaz. Imajo pa zlahka s tem probleme odrasli. Nekateri se sramujejo napadov svojega otroka v javnosti ali pa njegove prizadetosti, zapirajo ga v hišo ... Mi smo s hčerko v javnosti večkrat uprizorili kakšen »spektakel«, ampak sva z ženo to sprejela kot popolnoma normalno situacijo. Če predsednik države z neke terase skupini osemnajstletnikov vpije: »Gremo,

miška, to mi delaj,« potem je še dosti bolj normalno, da hčerki v javnosti sredi napada krčev potegnemo dol hlačke in ji rektalno damo zdravilo za prekinjanje epileptičnega statusa. No, v bistvu to ni dobra primerjava. Predsedniku ni nihče dal zdravila ... Ampak vsak ima pravico do napada. V glavnem, ja: s politično korektnostjo v resnih življenjskih preizkušnjah ne prideš nikamor: zdravo pamet ohraniš samo z nekakšno samodistanco, tudi ironično. Še potem se lahko zgodi, da del družine jemlje antidepresive, del družine ali kar oba si občasno skušata privoščiti kakšno pivo, dve, tri ... Konflikti v drami deloma temeljijo na najinih resničnih občasnih prepirih iz tistega časa, ampak so v tekstu dosti bolj rušilni, kot so bili pri naju, pač zaradi ujemanja s temeljnim zapletom, ki pa, hvala bogu, ni postal tudi najin.

Simona, kakšna replika?

Simona: Popolnoma se strinjam z Andrejem, da je treba o teh stvareh spregovoriti! To, da starši zapirajo svoje otroke v hiše, da drugi ne bi videli njihovih napadov, je srednjeveška miselnost, ki jo je treba na vse možne načine in z vsemi možnimi sredstvi razbiti ali vsaj premakniti na raven novega veka.

In umetnost je eno izmed sredstev, s katerim se da to narediti. Zdi se mi, da se moram kot umetnica ves čas zavedati svoje politične funkcije in odgovornosti. Glede zdravstvenega sistema pa: kako pojasniti zdravstveni sistem Republike Slovenije? Spomnim se – pred mnogimi leti je obstajal zdravstveni sistem. V začetku devetdesetih je bil vsaj še poskus zdravstve-



nega sistema. Od tam pa je, namesto da bi šlo navzgor, šlo vse samo navzdol. Zato mislim, da zdravstvenega sistema ni. Je pa birokratski, in to zelo trden.

Pisatelj Aleš se poleg vseh izzivov, ki mu jih nalaga nekoliko drugačen družinski vsakdan, sooča še z izzivi prekarnega delavca v kulturi. Andrej, kako sam dojemaš svojo pozicijo? Vidiš del svojega poslanstva tudi v »ozaveščanju« (v primeru *Hura, Nosferatu!* tudi s tako specifičnimi temami, kot je sindrom Dravet)?

Andrej: Jaz temu ne bi rekel »ozaveščanje«, raje »razmišljanje«. Skozi ta tekst – pa tudi svoje prejšnje tekste – sem razmišljal o lastnih reakcijah na razne pojave, dogodke. Nisem komentiral dogodkov – učil sem se razmišljati o njih, tudi o sebi. Razmišljati o tem, kaj so normalnost, sočutje, odgovornost, kje so meje tega, kar človek še prenese. Sindrom Dravet je mogoče marginalna zadeva, v Sloveniji te diagnoze nima več kot mogoče deset otrok, je pa spopadanje z osebno katastrofo in občutkom krivde univerzalna stvar. Predstavim lahko nekaj krutih medicinskih situacij, ki so v tej družbi, obsedeni z »normalnostjo«, glamurjem in finančnim uspehom, čisto nerazumljene, prezrte in odvečne – temu lahko rečemo ozaveščanje. Ampak neki profesor, ki ga zelo cenim, je zadnjič na televiziji omenil, kako rad pove študentom, da se lahko iz dobrega romana naučijo celo več kot iz učbenikov prava in kriminologije. Mislim, da je hotel povedati točno to: da te lahko literatura uči razmišljanja, ne pa samo podaja informacije, kot počne Google. Kar se pa tiče prekarcev, je to povezano: očitno smo zadnjih nekaj let končno dobili oblast, za katero je razmišljanje strošek. Niti sami nočejo več razmišljati: raje za par sto tisoč

evrov najamejo strokovnjake, ki jim bodo pomagali dokazati, da imajo oni prav. To je dober strošek. Kulture in izobraževanja nočejo financirati, ker je to strošek, ki ne utrjuje oblasti. Še več – sama ideja, da naj bi ljudje razmišljali, je dolgočasna; ljudje smo postali enostavno nadležni. Še najbolj zafukani komunisti so se vsaj zanimali za to, kaj pišejo literati, tudi tisti najbolj kritični. Stalin je osebno telefoniral Pasternaku, kaj misli o Mandelštamovi aretaciji. Čeprav Pasternak ni smel objavljati, je Stalin skrbel, da je imel sredstva za preživetje. Danes pa tega ne potrebujemo več, ker novi model iPada z desetkrat boljšo grafiko na igrinah preglaši vsako misel. Torej, le če napišem dramo, ki bo bolj atraktivna kot *Angry Birds*, bom mogoče prepričal kakšnega pripadnika naše elite. Težko jo bom. Če se pa ob tem mojem tekstu kdo vsaj malo poglobi sam vase, bom zelo srečen. Pa čeprav sem za ta tekst dobil svoj najnižji honorar doslej. Kaj hočemo, zdaj je čas, da za razmišljanje plačujemo bankirjem, ne pa živim ljudem.

Simona: Lahko rečem le, da se podpišem pod vse, kar je rekel Andrej, oziroma dodajam samo: v resnici je še slabše.

Pogovarjala se je Simona Hamer

With political correctness you get nowhere in serious life trials

Interview with Andrej E. Skubic and Simona Semenič

The Prešeren Fund Award for the novel *How Much Are You Mine?* (*Koliko si moja?*, Beletrina, 2001), the Kresnik Award for the début novel *Bitter Honey* (*Grenki med*, DZS, 1999), *How Much Are You Mine?* and *Just Come Home* (*Samo pridi domov*, Modrijan, 2014), winning the Cankarjeva Založba competition for the best contemporary novel with *Popcorn* (*Popkorn*, Cankarjeva založba, 2006), the 2007 Župančič Award for *Popcorn* and the Sovre Award for the translations of *Gertrude Stein: a Reader* (*Gertrude Stein: Čitanka*) and the novel *How Late It Was, How Late* (*Kako pozno, pozno je bilo*) by James Kelman. Six novels, one short story collection, three plays, a scientific monograph *Faces of the Language* (*Obrazi jezika*, Beletrina, 2005), countless translations ... the summary of the key milestones on the professional path of the writer, translator and playwright Andrej E. Skubic.

The Grum Award for the plays *5boys.si* (*5fantkov.si*, 2009), *24hours* (*24ur*, 2010) and *seven cooks, four soldiers and three sophias* (*sedem kuharic, štirije soldati in tri sofije*, 2015), award-winning performances in almost all Slovenian theatres, acclaimed performances abroad, the authorial projects *I, the Victim* (*Jaz, žrtev*, 2007), *43 Happy endings* (*43 srečnih koncev*, 2010), *The Second Time* (*Dругič*, 2014), leading the Preglej playwriting lab and numerous (international) playwriting workshops, managing Glej Theatre, working as a dramaturg, as a producer ... the summary of key milestones on the professional path of the playwright, dramaturg and performer Simona Semenič.

Hurrah, Nosferatu! (*Hura, Nosferatu!*) is their first professional cooperation. They enter it in the – seemingly atypical – roles of the playwright and the director.

Andrej, we know you as a multi award-winning writer and translator, so far you have tackled drama three times; *The Infinite Numbered Days* (*Neskončni šteti dnevi*, SNG Nova Gorica, 2009), *Hurrah, Nosferatu!* (2007) – which won you the Grum Award nomination in 2009 and *Pavla Above the Precipice* (*Pavla nad prepadom*, Mladinsko Theatre Ljubljana, 2014). Where do you perceive the key differences between prose and drama, and does it influence your process of writing? Does the fact that a play is, in a way, a »half-baked product«, which requires a mediator before it comes to the addressee, present a special challenge?

Andrej: Well, of course I've always loved theatre, but it was so fabulously alien to me that I've never seriously thought to write for it. Prose, that sitting behind the computer in the intimacy of a room, was a lot closer to me than socialising with actors, directors, dramaturgs, stage designers ... But the events around the staging of *Fužine Blues* (*Fužinski bluz*), performed at SNG Drama Ljubljana (2005) on Janez Pipan's initiative, excited me to the point that I wanted to write a text that was totally mine. Truly banal: look, I write some lesbian fantasy scene in the novel and then SNG Drama casts two fantastic actresses, Aleksandra Balmazović and Saša Mihelčič to act it out? It doesn't get better than that! But surely I can write something better! So I had to go on. *The Infinite Numbered Days* was then created as an adaptation of a short story

into a play. Yes, letting the »half-baked product« go to other people, ones you have to trust, is a special kind of a challenge, but so far, thank god, it's always been good ... Particularly the staging of *Pavla Above The Precipice* knocked me over – in a good way, I mean – I had the feeling this wasn't my text at all, that I was watching something completely new. It was only when I was translating the surtitles into English that I realised they hadn't changed a thing, they had just cut less than a quarter ... The contribution of the entire team was so immense that the performance went far beyond the text. This, to me, is the charm of writing for theatre.

Simona, we know you as a successful playwright with several awards, and although you have a number of per-



formances behind you that you authored – *A Fistful of Empty Hands (Polna pest praznih rok, 2001), Solo Without Talon (Solo brez talona, 2003), SheSaid (2005), Out (Iz Principa, 2009), Who's Next? (Kdo je naslednji, 2011), ... – and also many in which you also performed I, the Victim (Jaz, žrtev), The Second Time (Drugič), we rarely meet you in the role of a director. How did this cooperation come about? What attracted you?*

Simona: I've often been asked to try and direct my own texts, but somehow I didn't want to put myself into a role which would require interpreting myself. Because I know the theatre process, I'd be afraid of moments when I couldn't defend or justify my text to the actors and when the insecurity of Simona, the playwright, becomes a liability rather than an asset. My participation in *Hurrah, Nosferatu!* started with an e-mail. Andrej wrote to me, asking if I'd be interested in directing his text, and my first reaction was no, no, no, absolutely not ... then I slept on it and re-thought it and said: why not. What particularly attracted me to the project is of course my personal experience with epilepsy and the challenge of dealing with this topic through the perspective of someone else. Andrej's life is marked by the disease in a different way than mine is – his daughter has Dravet syndrome, a much more severe form of epilepsy than I have. And the more I thought about it, the more I was looking forward to the possibility of an alternate look ...

Andrej, *Hurrah, Nosferatu!* is an emphatically personal play. Can you say something about the genesis of the text? What made you chose the dramatic form over a novel?

Andrej: All stories written, after all, are somewhat personal. Your starting point is an experience, a situation or an event that touched you deeply and with which you want to make peace. You're always revealing yourself. Of course, the experience with a daughter who developed as an ordinary baby for the first six months, then initially got her first epileptic seizures, and was soon diagnosed with the syndrome whose very prognosis included cognitive impairment, irresponsiveness to therapy, the possibility of psychosis and a relatively high mortality, was the strongest experience in my life. Compared to something like this, everything pales in your head, all love traumas or social scandals and injustices. This goes straight to your core, you need to digest it. My wife and I were digesting it a day at the time, little by little. But it's extremely difficult to put to words; I had restraints to write about it for others. I tried for the first time in the period when the disastrous phase of my daughter's illness was still on-going, in the short story *It's nothing bad (Nič hudega ni, Madhouse / Norišnica, 2004)*. Kajetan Kovič once wrote: »when it hurts, it's neither an iamb nor a trochee«; I wrote that story when we were still living with it day by day, when it still hurt. My daughter was lucky, after a couple of difficult years she went through this phase of the disease quite well. Finally, we found a relatively successful combination of medications, so the feeling of immediate everyday danger eased, although various other problems remained. Maybe then came the time for »an iamb or a trochee«. I wanted to write a text about those feelings, when you're looking for survival strategies in extremely stressful times. My wife and I coped in ways that were different,



yet somehow similar, so we were a well-tuned team. Of course, there were conflicts – some are shown in the text in a slightly caricatured way – but we found common ground in some sort of strategy of dark humour, and self-irony that helped us retain sanity. Thank god that two so similar, but also complementary different, humans found each other. The conflict, however, was definitely a dramatic one, not novelistic. I wanted an image of a split, its insolubility; in a novel I wouldn't be able to avoid precise reflections, descriptions that I'm not actually capable of putting together in a credible way. I don't even know if I wanted to read them. This state of mind can only be shown, performed. Everything else, a spectator must reflect on one's own.

Simona, you spoke about your illnesses in the text *solo I, the Victim* and in the sequel *The Second Time*. Critic Blaž Lukan calls this approach an auto-referential verbalisation of a theme, and in both cases, the text is conceived as a direct address to the audience, or reader, compared to Andrej's classically dramatic form, a rather radical procedure.

Simona: What immediately attracted me to *Hurrah, Nosferatu!* is his honesty and the fact that he exposed himself and his family in a very direct way and that he spoke very openly about their everyday life. And it's this honesty that I find admirable and feel very close to. This is why I feel it is so important that the text is staged. Although I fear that our performance or our interpretation of Andrej's text is not exactly what he



might have imagined or wished ...

***Hurrah, Nosferatu!* develops the duality written in the title to two parallel and intertwining stories; the frame shows Aleš, a writer, who through his writing process is dealing with the death of a daughter with Dravet syndrome, while the other storyline consists of images of the everyday life of a family with a special-needs child. Where was your primary focus?**

Andrej: I didn't want to write a family story of a child with a malign epileptic syndrome; it's the one I'm still living today anyways, although it's calmer than it was six years ago. I wanted to write a story about death that destroys the family and how people deal with it, or don't.

Simona, which key segment did you want to emphasise in the performance, and why?

Simona: In one of the emails that Andrej and I were sending back and forth, he – only half-jokingly – wrote that I'm not Vida and I should not put myself in her place. And despite the fact that I'm crystal clear that Vida's medical anamnesis is different from mine, I feel his fear was justified. Despite the fact that father's sense of guilt is the main theme that Andrej was interested in, I found it important to put emphasis on Vida; her will to live, her purity, her innocence. And at the same time, guilt, of course, which in one or another form is present in all of us – you're guilty because you're alive ... I feel guilty that I have

epilepsy, because my parents suffered for this, because my brother was pushed to the background and so on. And this guilt is such a redundant component of our lives ... I have epilepsy; that's the way it is, but I don't need to feel guilty because my mother is sad and my mother doesn't need to feel guilty if I have a seizure. What does Kurt Vonnegut say: So it goes.

One of the directorial interventions is music, which enters the performance through Vida's elder brother Luka.

Simona: I found the character of Luka to be one of the weaker points of the play, as he somehow disappears through the text: he's there, and then he isn't and he appears again, and he vanishes a little ... From the dramaturgical aspect, his role seemed crucial, because he's the only one who takes her as she is; he even says it in the text, *She's not ill, she is she! And in a way it's fine that Vida has Dravet syndrome. Then she's pretty and white and she cuddles so much. She's something special.* Luka is learning how to play the guitar and has a band with his classmates called *Hurrah, Nosferatu!* and so I, in the desire to support Luka's character and have live music in the performance, concluded that it would be the best if Luka were the musician of our performance, Boštjan Narat.

Another prominent element are two poems by Andrej's daughter Lana that are included in the performance.

Simona: In addition to two experts for epilepsy and neuropsychology, Dr Igor M. Ravnik and Dr Vali Tretnjak Glavič, we also invited Andrej and his wife Klara, and it was then that Andrej told us that Lana writes

poetry and prose. He sent them to us and we found them so beautiful, so perfect in contents and form that we all – the entire team – immediately wanted to include them in the performance. And quite instinctively we also found the spots in the performance where they fit very quickly. To me, on a conceptual level, it meant an additional reinforcement of Vida's character and my desire to present her beauty, her will to live. Yes, if Aleš got his defender in Vida, I thought in this process I had to act as Vida's advocate.

The play opens a series of questions; from the stigmatisation (of children), the reorganisation of a family and misunderstanding they face from extended family and society, the critique of the healthcare system, etc. ... Andrej, did you question »political correctness« in the process of writing? – during rehearsals we discussed a lot about how we didn't want to present Vida merely as a sick child, and that we wanted to show the Petrač family in harmony with Nataša's line: »We're normal, we just need to follow the rules.«

Andrej: We have certainly always perceived our daughter as an ill child – but ill in the sense of a child who needs help, who most likely will never be able to take care of herself. But at the same time we've never wanted to give her an impression that there's anything wrong with her. After all, she didn't even know about her seizures; if she did know that a moment ago we'd been walking through the park and then suddenly she woke up in a hospital following an epileptic seizure, this was normal to her. We were constantly worried about the moment when she'd finally

realise she's »different« and how painful this would be for her. But this came to the surface very rarely. Because she attends a school for children with special needs who have very different abilities, she takes it for granted that some people can do certain things and some can't. She kind of accepts that at the age of fourteen she cannot do addition above ten, although her seven-year-old brother can, but what can we do; she's still dreaming that one day she'll drive a car and have children, like her mum, and there's no need to destroy these dreams for her. She's normal in that she's happy and sad, loving and loved, that we have fights with her over her behaviour just like we would with any other teenager. To herself, she's definitely normal like I'm normal to myself. Some people are ashamed of their child's attacks, or developmental challenges, they lock them up ... We often put on a spectacle with our daughter, but my wife and I simply demanded some sort of recognition that these situations are normal. If the president of the country yells at a group of 18-year-olds from some terrace: »Yeah, baby, do this to me,« then it's a whole lot more normal that we pull down our daughter's knickers when she seizes in public and administer the medication to stop an epileptic seizure rectally. Actually, this is not a good comparison. The president wasn't administered medication at all ... But anyone has a right to a seizure. Generally, yes: with political correctness you get nowhere in serious life trials: you only retain sense with some healthy self-distance, irony, too. And even then it can happen that a part of the family is on anti-depressants, while another, or both, occasionally try to indulge in a beer, or two, or three ... conflicts in the play are partly based on our actual occasional

fights in that time, but the ones in the play are far more destructive than ours were, so that they fit into the fundamental conflict, which ,thank god, wasn't our conflict.

Simona, a riposte?

Simona: I totally agree with Andrej that we must speak up about these things! Parents locking up children inside so others don't witness their seizures is a mediaeval mentality that needs to be shattered in any way and by any means possible, or at least moved to the level of the modern age. And art is, in a way, the means by which it can be done. I think that as an artist I must constantly be aware of my political function or responsibility.

About the healthcare system: explain the healthcare system of the Republic of Slovenia? I remember that – many, many years ago – there was some sort of a healthcare system. In the beginning of the 1990s, there was an attempt of a healthcare system, but from there, instead of going upwards, it has only gone down. So I think there is no healthcare system. But there is a bureaucratic system, and a very solid one at that.

In addition to all the challenges that his slightly different daily family life poses to him, Aleš, a writer, also faces the challenges of a precarious worker in the field of culture. Andrej, how do you perceive your own position? Do you see a part of your mission in the »awareness-raising« (in the case of *Hurrah, Nosferatu!* also about such specific things as Dravet syndrome?)



Andrej: I wouldn't call it »awareness raising«, but rather »thinking«. Through this text – and my previous texts – I've been thinking about my own reactions to different phenomena, events. I didn't comment on events – I learnt how to think about them and about myself. To think about what is normality, what compassion, what responsibility and where are the limits of what a human can bear. Dravet syndrome may be a marginal thing, perhaps about ten children have this diagnosis in Slovenia; but fighting a personal disaster, the feeling of guilt, is a universal thing. You can present a series of cruel medical situations that in this society, obsessed with »normality«, glamour, financial success, are completely misunderstood, ignored and redundant – we can call this raising awareness. But a professor I greatly respect said

the other day on television how he likes to tell students that they can learn more from a good novel than they can from law and criminology textbooks. I think this is exactly what he wanted to say: that literature can teach you thinking rather than just providing information, like Google does. As far as precarious workers are concerned, this is all connected: apparently, in the last couple of years we finally have a government which considers thinking a cost. They themselves no longer want to think: they hire experts for a couple of hundred thousand Euros to help them prove how right they are. This is a good cost. Culture and education; they won't finance that – it's a cost that doesn't reinforce power. Even more – the very idea that people should think is boring; people have simply become a nuisance. Even the most

fucked-up communists have always been at least interested in what authors write, even those most critical ones. Stalin personally telephoned Pasternak to hear what he thought of Mandelstam's arrest. Although Pasternak wasn't allowed to publish at all, Stalin made sure he had the means to survive. Today we don't need this anymore, because the new iPad model with graphics ten times better for the games overrides any thought. Perhaps I should write a play that would be more attractive than *Angry Birds* and maybe I'll convince a member of our elite. Not very likely. But if anyone at least delves a little deeper watching it, I'll be happy. Despite the fact that this text yielded the lowest fee of them all. What can we do, times are such that we pay bankers for thinking rather than living people.

Simona: All I can say is that I subscribe to everything Andrej has said, if anything, I'd add that things are even worse, really.

Interview by Simona Hamer
Translated by Barbara Skubic



Pesem za Jureta

O Jure močen si kot sto vragov
zelo sem zaljubljena v tebe
kako si zabaven si zelo bi te poljubila
mislím da si doma v šoštanju
zelo si mi všeč tako da bi te objela
zelo si luštkan in bi te vidla vsak dan v šoli
zato da se bi s tabo pogovarjala o ljubezni
kajne da je to lepo
tudi če bi šla skupaj na žale svečko prižgat
babi gabi
zelo bi bila vesela najinega obiska
sej sem ti že neki pravla o njej
aneda se spomniš to je bilo leta 2010
a veš da ti bom sama sprintala eno pesem
ko poje o tebi
mislím da ti bo všeč moje pesmi so zelo
dobre aneda
se spomniš ko me je prišel iskat dedi tine
in babi gabi
sta me prišla iskat skoraj vsak četrtek
en četrtek pa me je prišla iskat tina klarič
od moje mame sodelovka in sem ti poma-
hala ven iz avta

Poem for Jure

O Jure you are strong as hell
I am very much in love with you
you are so funny you are I would very
much kiss you
I think you are from šoštanj
I like you so very much I would embrace
you
you are very cute and I would like to see
you everyday at school
to talk with you about love
isn't that lovely
maybe we could go together to žale to li-
ght a candle for granny gabi
she would be very pleased to see us
I have already told you something about
her
you remember dont you it was in 2010
look I will print for you a song which sings
of you
I think you are going to like it my poems
are very good arent they
you remember when grandpa tine and
grandma gabi came to pick me up
they would come to pick me up nearly eve-
ry thursday
but one thursday tina klarič came to pick
me up
who works with mum and I waved to you
from the car

Lana Skubic

Translated by Srečko Fišer

Igor M. Ravnik

Epilepsija v življenju in na odru

Ko v življenje udari bolezen, posebej če gre za bolezen pri otroku in še posebej, če je to težka bolezen, se udeležencem drame zamajajo temelji. O tem govori predstava *Hura, Nosferatu!* Odprli ste gledališki list in berete to pisanje pred predstavo. Počakajte, naj svoje najprej opravi gledališče! Dramatik je napisal besedilo, gledališki ustvarjalci so ga postavili na oder. Iz tega pogleda bo gledalcem vse bolj ali manj jasno, ganljivo, grozljivo, kdaj tudi zabavno, šokantno, tragično. Poučno?! Umetnost pač ni tečaj higijene in zdravstvene vzgoje, ki jo predavajo medicinske sestre otrokom na obveznih sistematskih pregledih. Recimo raje, da je ta gledališki dogodek tudi osveščevalno dejanje ...

Izkoristiti želim torej priložnost, da o zdravljenju epilepsije v svetu in pri nas spregovorim iz diplomatskega strokovno-humanitarnega položaja tudi v prostoru gledališča, kjer se o tem običajno ne govori. Epilepsija je namreč ena od najpogostejših nevroloških bolezni. Zgodi se lahko komurkoli in v katerikoli starosti. Označevanje te bolezni kot »nekaj posebnega« je zato neustrezno. Nekoč so epilepsijo imenovali sveta bolezen, latinsko *morbis sacer*, tudi v slovenščini se ji lahko reče padavica ali božjast, torej nekaj »božjega«. Negativno označevanje (stigmatizacija) te bolezni

je bilo povezano – včasih in tudi še danes – z verovanji, prenesenimi iz davnine. Vsekakor pa je že starogrški zdravnik Hipokrat vedel, da epilepsija (»bolezen z napadi«) ni nič bolj božja od katerekoli druge bolezni, da jo lahko povzročajo poškodbe možganov ter da se lahko prenaša v družinah.

Teden dni, preden so me iz SNG Nova Gorica zaprosili za ta prispevek, se je končno zgodilo, da je epilepsija in z njo epileptologija, stroka, ki se ukvarja z zdravljenjem oseb z epilepsijo, znana kot »uboga pastorka na dvorišču nevrologije« – saj po sredstvih, ki so namenjena za raziskave in zdravljenje te bolezni, v svetu in pri nas močno zaostaja celo za drugimi možganskimi boleznimi –, vendarle prišla na vrsto: Svetovna zdravstvena organizacija (SZO) je 26. maja 2015 po oceni bremena, ki ga ta bolezen povzroča prebivalstvu planeta, sprejela resolucijo: Globalno breme epilepsije in potreba po usklajeni akciji na ravni držav, da se lotijo posledic na področju zdravja in sociale ter seznanjajo javnost s to boleznijo.

Pogostost in narava epilepsije ter zbirna ocena stanja pri nas

Epilepsijo, bolezen s ponavljajočimi se napadi (posledica nepravilnega delovanja možganskih celic), ima v razvitem svetu okrog 1 % prebivalcev, skupaj 50 milijonov ljudi po vsem svetu, nekajkrat več ljudi pa doživi vsaj en napad, ki je povezan z možgansko boleznijo, a se kasneje napadi ne ponavljajo; pomeni, da te osebe nimajo epilepsije. Najpogosteje se bolezen pojavlja v otroštvu in po 65. letu starosti, v vseh rasah in socialnih slojih. Ne gre za enovito bolezensko stanje. Poznamo več deset podvrst epilepsije, medicinsko so največ-



krat opredeljene kot »sindromi«. Združujejo se po podobnostih v pojavljanju in obliki napadov, v poteku in odzivu na zdravljenje ter v spremljajočih psiholoških posledicah – četudi vseh vzročnih dejavnikov njihovega nastanka dostikrat ne poznamo.

Sindrom Dravet, za katerim boluje deklica v gledališki igri, je eden od šele nedavno opisanih sindromov, o katerem stroka razume že marsikaj, pri zdravljenju pa je le deloma uspešna. Imenjuje se po ugledni francoski klinični raziskovalki epilepsije dr. Charlotte Dravet, je pa ena od hujših, na srečo redkih, podvrst otroške epilepsije. Poznamo še veliko podvrst, med njimi tudi hujše, a veliko je tudi epilepsij, ki so lažjega poteka; te so na srečo pogostejše. Pri večini oseb z epilepsijo so tveganja povezana predvsem s poškodbami med napadom,

odvisno od oblike le-tega. Pri redkih obstaja tudi nevarnost nenadne, nepričakovane smrti. Zdravila pri večini bolnikov preprečijo napade. Za ostale – če z ustreznimi zdravili napadov ni moč nadzorovati, govorimo o trdovratnih epilepsijah – je na voljo še dietno in za manjšino tudi nevrokirurško zdravljenje; le-to je lahko zelo uspešno.

V Sloveniji je za obravnavo večine oseb z epileptičnimi napadi poskrbljeno razmeroma dobro, po nekaterih vidikih bolje kot marsikje po svetu. Otroška epileptologija se je razvila že v šestdesetih letih prejšnjega stoletja, potem ko je 1954 kot darilo naprednih ameriških Slovenk iz Clevelanda prišel na Otroško kliniko v Ljubljani prvi EEG – aparat za snemanje možganskih valov, elektroencefalografijo. Danes so pri

nas na voljo diagnostični pripomočki in protiepileptična zdravila, praviloma brez doplačil. Specialisti so izobraženi, strokovni timi zavzeti in požrtvovalni. Tekoče se delovno povezujejo z najuglednejšimi mednarodnimi epileptološkimi centri. Kirurško zdravljenje poteka večinoma v tujini, kamor slovenski strokovnjaki po timskem posvetu napotijo bolnike v vrhunske centre, s katerimi domači specialisti tesno sodelujejo.

A ta načelna ocena in pohvala za stroko ne pomeni, da je vse urejeno, kot je treba. Slovenija nosi nekaj nesprejemljivih političnih rekordov, na katere ne more biti ponosna. Kadrovske je epileptologija zaradi strokovno neutemeljenih političnih odločitev (omejitev oz. nezaposlovanje prepotrebne kadra) in neodzivnosti zdravstvene politike na izražene strokovne potrebe močno okleščena in razvojno ogrožena. Med regijami so v dostopnosti multidisciplinarnе obravnave (kar pomeni obravnavo medicinskih, psiholoških in socialnih vprašanj) zelo velike, strokovno neutemeljene in nepravilne razlike. Čakalne dobe za obravnavo najtežjih bolnikov – odraslih kandidatov za kirurško zdravljenje – so nesprejemljivo dolge, najdaljše v Evropski uniji. Trajanje bolniških odsotnosti zaradi epilepsije je med najdaljšimi v primerjavi z drugimi diagnozami. Možnosti za raziskovalno dejavnost so skrajno omejene.

Društvo Liga proti epilepsiji Slovenije

Strokovno-humanitarno društvo Liga proti epilepsiji Slovenije je član Mednarodne lige proti epilepsiji, ene najstarejših mednarodnih strokovno-humanitarnih organizacij. Zagotavlja vrsto podpornih dejavnosti, ki lajšajo življenje oseb z epilepsijo.

Organizira redna srečanja skupine staršev otrok z novo ugotovljeno epilepsijo, skupine za samopomoč (med 5 in 11 skupin je sočasno aktivnih po regijah dvomilijonske države), tedenski svetovalni telefon za psihosocialna vprašanja, laični program spremljanja bolnikov na posege v tujino. Organizira vsakoletne podiplomske mednarodne šole praktične epileptologije, izobraževanje pedagogov v vrtcih in šolah, podpira razvoj področnega multidisciplinarnega sodelovanja na primarni in sekundarni ravni. Posebej pozorno spremlja možnosti za zagotavljanje čezmejnega sodelovanja, saj je to nujno potrebno za bolnike iz majhne države, če bolujejo za katero od redkih bolezni; v našem primeru se to vprašanje pojavlja zlasti pri osebah s katero od podvrst kirurško ozdravljive epilepsije. Še zlasti je to pomembno, kadar terja bolezen obravnavo v zelo visoko specializirani ustanovi, kjer so zbrane najboljše izkušnje o redkih bolezenskih primerih, ki se stekajo v tak center iz mnogih evropskih držav. Slovenski model tekočega sodelovanja s tujino in spremljanje bolnikov (laično ali strokovno) v tujino ter opozarjanje na posebnosti v zagotavljanju čezmejnega zdravstvenega varstva za osebe z epilepsijo je deležen javnega priznanja na mednarodni ravni.



Vabilo

Gledalka / gledalec oz. bralka / bralec, ki si ob gledališkem doživetju in branju tega prispevka zastavlja vprašanja o epilepsiji, na katera bi želel psihosocialni nasvet, ali morda želi predlagati izobraževanja pedagogov ali svetovanje staršem, se lahko obrne na naslov:

Društvo Liga proti epilepsiji Slovenije,
Ulica stare pravde 2, 1000 Ljubljana,
tel. 00386 1 432 9393; na Svetovalni telefon
EPITEL pa ob četrtkih med 16. in 19. uro na
isto telefonsko številko; ali na e-mail
epilepsija@epilepsija.org.

Avtor prispevka prim. Igor M. Ravnik, dr. med. spec., je Ambasador epilepsije (Mednarodna Liga proti epilepsiji) in nekdanji predsednik Društva Lige proti epilepsiji Slovenije.

Igor M. Ravnik

Epilepsy in Life and Onstage

When a disease strikes in life, particularly if it is a disease in a child, and particularly if it is a grave disease, those who are part of the drama are shaken to the core. This is what the performance *Hurrah, Nosferatu!* talks about. You've opened the theatre programme and you're reading this article before the performance. Wait, let the theatre work its magic first! The playwright has written the text, the theatre artists are putting it onstage. Their perspective will make the theme more or less clear to the audience, but also touching, horrifying, at times, entertaining, shocking, tragic. Instructive?! Art is not a course in hygiene and health education that nurses give to children during compulsory medical check-ups. Let's rather say that this theatre event is an awareness-raising act ...

From my diplomatic expert-humanitarian position, I would like to take the opportunity and speak about the treatment of epilepsy in Slovenia and the world -- in theatre, where it is not often discussed. Epilepsy is one of the most common neurological diseases. It can occur in anyone, at any age. Denoting it as »something special« is inappropriate. Once upon a time, epilepsy was called a sacred disease, in Latin *morbis sacer*, and has been called *sacred disease* or *falling sickness*, in other

words, something linked to religion. The negative connotation (stigmatisation) of the disease has been linked – in days of yore and today – to beliefs inherited from the ancient past. But already the Greek doctor Hippocrates knew that epilepsy (»a disease with seizures«) is no more godly than any other disease, that it can be caused by brain injuries and that it can run in families.

A week before the SNG Nova Gorica asked me to write this article, it finally happened that epilepsy – and with it epileptology, the branch of medicine dealing with the treatment of persons with epilepsy, known as »the poor orphan on the courtyard of neurology« because the funding allocated for its research and treatment, throughout the world and in Slovenia, is seriously lagging behind even other brain illnesses – finally got its turn. On 26 May 2015, after evaluating the burden that epilepsy causes to the population of this planet, the World Health Organisation (WHO) adopted the resolution »Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications«.

The frequency and nature of epilepsy and the overall evaluation of the situation in Slovenia

Epilepsy, the disease with recurrent seizures (a result of abnormal brain cell activity) affects approximately 1 % of the population in the developed world, about 50 million people worldwide. Several times this number of people have had at least one seizure associated with a brain disease, but their seizures have not recurred; it means these persons do not have epilepsy. The disease most often occurs



during childhood and after 65 years of age, in all races and social strata. It is not a uniform condition. We know several dozens of epilepsy subtypes; medically, they're most often defined as »syndromes«. They are grouped together according to similarities in occurrence and form of seizures, in the course and response to treatment and in accompanying psychological consequences – although we often do not know all the factors that cause them.

The Dravet syndrome that affects the girl in the play is one of the very recently described syndromes, about which experts already understand plenty, yet are only partially successful in treating. Named after the respected French clinical researcher of epilepsy, Dr Charlotte Dravet, it is one of the most severe, but fortunately rare, subtypes

of childhood epilepsies. The subtypes are many, some severe, and some more benign; fortunately, these lighter ones are the most common. In the majority of persons with epilepsy the risks are linked primarily to the injuries caused by seizures, depending on what form they take. In rare cases there is a danger of sudden and unexpected death. Medications prevent seizures in the majority of patients. For the rest – if suitable medication is not enough to control the seizures, we talk about pharmacoresistant epilepsy – there is also dietary and neuro-surgical treatment; the latter can be very successful.

In Slovenia, the majority of people with epileptic seizures are relatively well cared for, in some aspects better than in many

places in the world. Pediatric epileptology was developed here as early as the 1960s, after the first EEG machine, the machine that records electrical brain activity, came to the Ljubljana Pediatric Clinic in 1954 as gift from progressive Slovenian American women from Cleveland. Today we also have diagnostic tools and antiepileptic drugs available, as a rule, without co-payment. The specialists are well educated, the expert teams dedicated and consummate. They are connected to the most-respected international epileptology centres. Surgical treatment mostly takes place in the top facilities abroad, where Slovenian experts refer patients after team consultations and work closely with consultant physicians.

But this general assessment and praise for the experts does not mean that everything is as it should be. Slovenia has some unacceptable political records that are nothing to be proud of. Due to professionally unfounded political decisions (limiting or preventing the employment of much needed staff) and the irresponsiveness of the healthcare policies to the articulated professional needs, epileptology is severely understaffed and its development is in danger. In terms of accessibility to multi-disciplinary treatment (meaning treatment of the medical, psychological and social issues) there are immense, professionally unfounded and unfair differences between regions. The waiting periods for treatment in the most severe cases – adult candidates for surgical treatment – are unacceptably long, the longest in the European Union. The amount of sick days because of epilepsy is among the highest compared to other diagnoses. The research possibilities are extremely limited.

The Slovenian League Against Epilepsy

The professional and humanitarian association, the Slovenian League Against Epilepsy is a member of the International League Against Epilepsy, one of the oldest international professional-humanitarian organisations. It provides a series of supporting activities that ease the lives of people with epilepsy. It organises regular meetings of support group for parents with children with epilepsy, self-help groups (between 5 and 11 groups are operating in different regions of our country with its two million inhabitants), a weekly telephone counselling hotline for psycho-social questions, a programme of lay caregiver companions for patients referred to treatment abroad. It organises an annual post-graduate international school of practical epileptology and training for educators in kindergartens and schools as well as supports the development of multi-disciplinary cooperation in this field on the primary and secondary levels. It monitors particularly attentively the possibilities to provide cooperation across borders, as this is essential for patients from a small country; in our case, this question arises above all in persons in the subcategory of surgically treatable epilepsy. This is especially important when the disease requires treatment in highly specialised institutions, where they have gathered the best experience about rare cases of the disease that have come to such centres from many European countries. The Slovenian model of cooperation with international centres and (lay or professional) caregivers accompanying patients abroad and drawing attention to particularities in ensuring international health care for persons with epilepsy has been a subject of praise on the international level.



Invitation

The spectator or reader who has questions about epilepsy arising from this theatre event or reading this text and would like psychosocial advice, or who may wish to recommend education for teachers or counselling for parents, can turn to

Društvo Liga proti epilepsiji Slovenije
(The Slovenian League Against Epilepsy),
Ulica stare pravde 2, 1000 Ljubljana,
tel. 00386 1 432 9393; or the telephone
counselling hotline EPITEL on Thursdays
between 16:00 and 19:00 at the same num-
ber; or email epilepsija@epilepsija.org.

The author of the article, prim. Igor M Ravnik, MD, spec., is an Ambassador for Epilepsy (as named by the International League Against Epilepsy) and a former president of the Slovenian League Against Epilepsy.

Ljubezenski roman

Dolgo nazaj je stala šola.

V to šolo sta hodila Jure in Lana.

Jan je hodil v 6.a Lana pa v OVI 2.

Hej, kaj pa če se bi poročila? je vprašal Jan. Seveda se lahko. Saj nisva premajhna, Jaz pa mislim da bi se lahko poročila, saj veliki se lahko poročijo.

Odločila sta se, da se bosta poročila kar v šoli. Lana je dobila izvrstno zamisel: morava pripraviti vse ostalo! In zmenila sta se za datum 26 februarja. Kdo bo pa nosil prstan? Ja, ti, Jure, si pozabil? Kaj pa priči? Tina in Anže! Kaj pa lepe pesmice vesele?

In je prišel ta dan. Čeprav je dežurni sedel v avli šole, sta si dala poljubčke in so riž metali. In so se norce delali iz njiju.

Živel sta v Fužinah v hiši, imela sta pet otrok: Anastazijo, Petro, Kajo, Nežo, Majo. Nista sadila zelenjave. Otroci so imeli napade in epilepsijo, grizli so si nohte. Jure in Lana sta jih skušala ozdraviti s peštano hrano, pa niso dovolili. Pa niso hoteli iti na sprehod. Hoteli so gledati v televizijo, hoteli so iti na računalnik.

Lana jim je rekla: dosti je bilo televizije in računalnika, morate jesti peštano hrano in iti na sprehod. In so ubogali. Potem so bili v redu in so ozdraveli. In srečno so živeli do konca svojih dni.

Love Novel

A long time ago there was a school.

Jure and Lana were pupils of that school.

Jure was in 6 a and Lana was in OVI 2.

Hey, what about getting married? Jure asked.

Of course we can. We are not too little. I do think we could marry, grown people can get married. They decided they would marry in the school. Lana had an excellent idea: we have to take care of everything else! And they agreed about the date 26 february. Who will be wearing the ring? Well, you, Jure, did you forget? And the witnesses? Tina and Anže! And the merry songs?

The day came. Though the supervisor was in the entrance hall they kissed and rice was thrown. And fun was poked at them two.

They lived in Fužine in a house and had five children: Anastazija, Petra, Kaja, Neža, Maja. They grew no vegetables. The children had attacks and epilepsy, they bit their fingernails. Jure and Lana tried to cure them with mash food but they wouldnt let them. And they wouldnt go for a walk. They wanted to look at the television and computer. Lana told them: enough of television and computer, you have to eat mash food and go for a walk. And they obeyed. Then it was ok and they were cured. And they lived happily ever after.

Lana Skubic

Translated by Srečko Fišer



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NETA – mednarodni gledališki festival 2015 v Bukarešti (28. 8.–4. 9. 2015)

Nova Evropska Teatrška Akcija – NETA je bila ustanovljena leta 2004 z namenom razvoja mednarodne gledališke mreže, od leta 2011 pa deluje kot kulturni zavod s sedežem v Ljubljani, nad katerim bdi Kulturno društvo B-51. NETA je nastala na pobudo sedanjih in nekdanjih ministrov za kulturo ter direktorjev gledališč in festivalov. Mreža deluje v različnih oblikah uprizoritvene umetnosti; njen namen je spodbujati festivalsko in sploh kulturno sodelovanje med evropskimi državami – izmenjavo predstav, umetnikov, koprodukcije, razvoj gledališkega in kulturnega prostora ipd. Povezuje pa tudi gledališke, filmske ter druge renomirane umetniške in kulturne ustanove z različnih koncev Evrope in širše. Danes povezuje mreža NETA 68 članic iz 20 držav, med katerimi so zastopana tudi društva, državne institucije in pomembnejši festivali z območja Vzhodne in Južne Evrope. Pomembna platforma, kjer je vidna razgibana dejavnost mreže, njene produkcije, plodnih sodelovanj in povezovanj, je NETA International Theatre Festival, ki se bo letos odvil prvič, in sicer med 28. 8.–4. 9. v Bukarešti. Osemdnevni program poteka pod sloganom »Gledališče – junak našega časa«. Videti bo moč trinajst gledaliških in plesnih produkcij iz desetih članic NETA. Organizatorji festivala so Narodno gledališče *I. L. Caragiale* Bukarešta, mreža NETA in UNITER. Slovenske barve bodo zastopale kar tri koprodukcije: *Hura, Nosferatu!* Andreja E. Skubica ter dve slovensko-makedonsko-bolgarski produkciji – *Ciril in Metod* dr. Jordana Plevneša ter *Tobeliya* Ljubomira Djurkovića; Prešernovo gledališče Kranj pa bo sodelovalo s svojo predstavo *Mrtvec pride po ljubico* Svetlane Makarovič.

NETA – International Theatre Festival in Bucharest 2015 (28/8–4/9/2015)

The New European Theatre Action – NETA was created in 2004 to develop an international theatre network, and has been operating since 2011 as a theatre institute with a seat in Ljubljana, managed by the B-51 Cultural Society. NETA was established as an initiative of present and former ministers of culture, and theatre and festival directors. The network promotes different forms of performing arts; its objective is to encourage festival and cultural cooperation between European countries – exchanging performances, artists, co-productions, development of theatre and cultural space etc. Today, NETA connects 68 members from 20 countries, including performing arts associations, state institutions and important festivals from eastern and southern Europe. An important platform showing diverse activity of the network, its production, fruitful cooperation and connections is the NETA Theatre festival, which will occur for the first time this year, between 28 Aug. and 4 Sept in Bucharest. The slogan of the eight-day programme is »Theatre – the Hero of Our Time«. Thirteen theatre and dance productions from ten NETA member states will be shown. The festival organizers are National Theatre *I. L. Caragiale* Bucharest, NETA and UNITER. Slovenian members will be represented by three co-productions – *Hurrah, Nosferatu!* by Andrej E. Skubic and two Slovenian-Macedonian-Bulgarian productions – *Cyril and Methodius* by Dr. Jordan Plevneš and *Tobeliya* by Ljubomir Djurković; the Prešeren Theatre Kranj will participate with its performance *A Dead Man Comes for His Sweetheart* by Svetlana Makarovič.



Član Evropske gledališke konvencije / Member of European Theatre Convention



Pobudnik gledališkega združenja NETA New European Theatre Action / Initiator of the NETA New European Theatre Action network



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