

HULOH Hepatos

Hrvatska Udruga Liječenih
i Oboljelih od Hepatitisa

Godišnji izvještaj

Hrvatske udruge liječenih i oboljelih od hepatitisa „Hepatos“

za 2011. godinu

Zaposlenih:

4

Hepatos tim

Tatjana Reić

Marijana Spaija

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Nera Grbić

Dodatne informacije o udruzi

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Bilten Udruge

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SADRŽAJ

Uvodna riječ Izvršnog tima

Postignuti rezultati

Financijski izvještaj

Uvodna riječ

Kao događaj koji je najviše obilježio proteklu godinu izdvajamo izbor predsjednice „Hepatos“, **mr.sc. Tatjane Reić, za predsjednicu ELPA-e (European Liver patients Association)** na godišnjoj Skupštini ove međunarodne organizacije, održane u Berlinu 31. 03. 2011. godine.

2011. godinu pamtit ćemo i po ponovnom imenovanju naše udruge za **National Focal Point za hepatitis** od strane Svjetske zdravstvene organizacije, za razdoblje 2012-2013. Hepatos je bio prva udruga koja je ovo priznanje dobila 2009. godine za razdoblje 2010-2011 i to na preporuku Ministarstva zdravlja.

Ponovno imenovanje naše udruge za National Focal Point za hepatitis najbolje potvrđuje da je Hepatos prepoznat i priznat od međunarodne i domaće stručne zajednice u borbi protiv virusnih hepatitisa, a rezultat je jedanaestogodišnje posvećenosti radu na poboljšanju kvalitete življenja i direktne pomoći oboljelima, preventivnih i javno zdravstvenih aktivnosti, zagovaranja i lobiranja, te izmjena zakonskih odredbi u interesu oboljelih, doprinosa demokratizaciji i antidiskriminaciji kao jačanja vlastitih kapaciteta.

Zadovoljstvo nam je da je u Hrvatskoj napokon dostupan i FibroScan®, uređaj koji tijekom pregleda na potpuno bezbolan način mjeri elastičnost i utvrđuje stupanj oštećenja jetre, zahvaljujući velikim dijelom i angažmanu Udruge Hepatos od prije dvije godine kada smo uređaj prvi predstavili na 6. Hrvatskom kongresu o infektivnim bolestima s međunarodnim sudjelovanjem. U siječnju 2011. godine su nabavljena dva uređaja koja će oboljelima biti dostupna u dva Referentna centra MZSS-a.

Na međunarodnoj razini sudjelovali smo na brojnim radionicama i kongresima, među kojima posebno izdvajamo **American Association for The Study of the Liver: The Liver Meeting 2011** održan u San Franciscu i **Viral Hepatitis Prevention Board Advisor Meeting** održan u Milanu, gdje je **mr. sc. Tatjana Reić izabrana za članicu savjeta** te organizacije.

Posebno ističemo i obilježavanje Svjetskog dana hepatitisa, koji je ove godine prvi put obilježen kao **prvi službeni Svjetski dan hepatitisa** koji ima potporu **Svjetske Zdravstvene Organizacije, 28. srpnja. Središnji događaj obilježavanja Svjetskog dana hepatitisa 2011.** u Hrvatskoj **bila je javna akcija na plaži Zrće**, popularnom ljetnom okupljalištu mladih u blizini Novalje na otoku Pagu.

Prepoznatljivost rada udruge potvrđuju i pozivi na **sudjelovanje u promocijama biografske knjige Ivana Gudelja**, bivšeg hrvatskog nogometaša, u kojoj je opisana i njegova borba s hepatitisom B. Tijekom 2011. godine Hepatos je sudjelovao na pet promocija „Hajdučke priče“ u Hrvatskoj i Bosni i Hercegovini.

POSTIGNUTI REZULTATI U 2011. GODINI

Međunarodne aktivnosti i zajednička informativno-edukativna kampanja sa Savezom oboljelih od hepatitisa RH

Na Godišnjoj Skupštini **European Liver Patients Association (ELPA)** održanoj u Berlinu 31.03.2011., predsjednica Hepatosa mr. sc. Tatajana Reić jednoglasno je izabrana, za razdoblje od 4 godine, za **novu predsjednicu** te organizacije. Dotadašnja predsjednica ELPA-e, gđa. Nadine Piorkowsky, koja je uspješno vodila organizaciju 4 godine predložila je mr.sc. Tatjanu Reić za svoju nasljednicu, što su svi članovi sa zadovoljstvom prihvatili.

Ove godine obilježili smo **prvi službeni Svjetski dan hepatitisa** koji ima potporu **Svjetske Zdravstvene Organizacije**. Datum 28. srpnja kao službeni Svjetski dan hepatitisa utvrđen je na 63. sjednici generalne skupštine SZO usvajanjem Rezolucije o virusnim hepatitisima, 21. svibnja 2010. Tema ovogodišnjeg dana hepatitisa obilježenog u sklopu kampanje „**Ovo je hepatitis...**“ bila je „**Hepatitis se može dogoditi svakome, svugdje. Saznaj. Suoči se.**“ Posebno je naglašen velik utjecaj ove epidemije, važnost informiranja, te potreba korištenja tih informacija u borbi protiv stigme koja je kriva za neznanje o ovoj epidemiji. Aktivnosti povodom obilježavanja ovogodišnjeg dana hepatitisa organizirane su u više od 70 zemalja diljem svijeta, pod koordinacijom WHA (World Hepatitis Alliance), krovne organizacije udruga oboljelih od hepatitisa sa više od 130 udruga članica iz 58 zemalja svijeta.

Kao član World Hepatitis Alliance-a u Hrvatskoj smo, zajedno s ostalim članicama Saveza oboljelih od hepatitisa (SOH RH), proveli niz aktivnosti vezanih za obilježavanje Svjetskog dana hepatitisa pod pokroviteljstvom Ureda Svjetske zdravstvene organizacije u RH, a uz podršku i sudjelovanje Referentnih centara MZSS za liječenje i dijagnostiku virusnih hepatitisa i kronične bolesti jetre te više od 40 liječnika/stručnjaka Zavoda za javno zdravstvo Gospića, Splita, Zadra, Rijeke, grada Novalje, Crvenog križa, Opće bolnice Koprivnica i drugih.

Kao i prethodnih godina, svim saborskim zastupnicima, liječnicima gastroenterolozima i infektolozima, ravnateljima zavoda za javno zdravstvo i predstavnicima medija **upućen je 501 dopis** s prigodnim informativno-edukativnim materijalima te pozivom na davanje potpore u obilježavanju Svjetskog dana hepatitisa i našem radu.

01. 07. 2011. Sudjelovali smo na **simpoziju povodom Svjetskog dana hepatitisa** na Klinici za infektivne bolesti „Dr. Fran Mihaljević“ u Zagrebu, gdje je član udruge održao predavanje „Hepatitis C – što učiniti s teško izlječivim bolesnicima? Kako može pomoći krovna europska udruga pacijenata ELPA (European Liver Patients Association)“? Osim predavanja bio je izložen i štand s informativno-edukativnim materijalima udruge.



Info dani na gradskim trgovima organizirani su 28. 07. 2011. u Križevcima i Đurđevcu, a 29. 07. 2011. i u Koprivnici gdje su se dijelili informativno-edukativni materijali i organizirala i akcija besplatnog testiranja.

Među ukupno **79 medijskih istupa povodom obilježavanja Svjetskog dana hepatitisa**, na televiziji, radiju, portalima i tiskovinama, posebno ističemo tv-priloge u udarnim informativnim emisijama svih televizijskih kuća s nacionalnom pokrivenošću, te intervjuje i najave na čak **19 radijskih postaja** s lokalnom i/ili nacionalnom pokrivenošću.

28. 07. 2011., na sam Svjetski dan hepatitisa, održali smo ovogodišnju **centralnu aktivnost obilježavanja Svjetskog dana hepatitisa u RH, javnu akciju na plaži Zrće na otoku Pagu**. U sklopu akcije, posjetiteljima plaže Zrće omogućili smo savjetovanje i besplatno/anonimno testiranje na HCV i HIV u šatoru Crvenog križa. Rezultat akcije, su osim 77 testiranih osoba, povećana svjesnosti hrvatske javnosti o problemu virusnih hepatitisa, što je i bio glavni cilj kampanje.



Sve aktivnosti udruge popraćene su vijestima i fotodokumentacijom na **web stranici** www.hepatos.hr.

U 2011. godini objavljeno je **40** vijesti o aktivnostima Udruge i čak **163** prevedene vijesti o najnovijim postignućima u liječenju i prevenciji virusnih hepatitisa.

U 2011. godini Hepatos je imao ukupno **120** različitih medijskih istupa, od kojih posebno ističemo tv-priloge u udarnim informativnim emisijama svih televizijskih kuća s nacionalnom pokrivenošću. Web stranicu naše udruge posjetilo je tijekom godine **73 177** posjetitelja koje smo informirali, educirali te po potrebi savjetovali i usmjeravali preko maila i on-line savjetovališta.



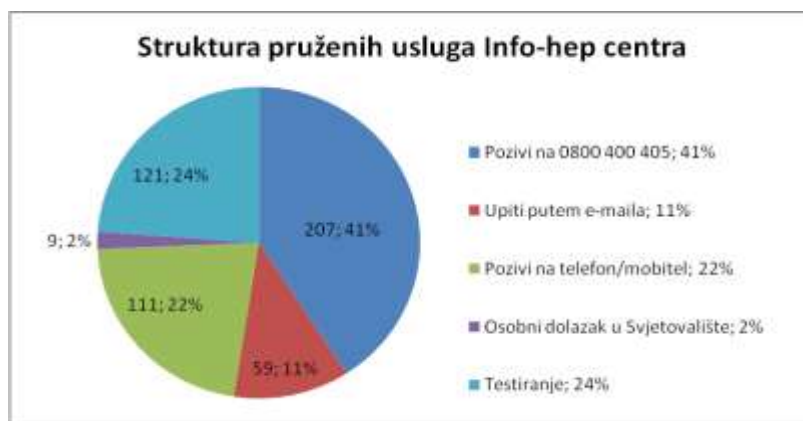
Pružanje podrške oboljelima i njihovim obiteljima

U skladu s ciljevima Udruge, definiranim Statutom, terminom „Info-hep centar“ definira se Hepatosov model za pružanje usluga informiranja o načinima prijenosa i posljedicama virusnih hepatitisa, zdravstvenog, psiho-socijalnog savjetovanja o ostvarivanju prava na liječenje, te anonimnog i besplatnog testiranja na virusne hepatitise i HIV.

U 2011. godini u našem „Info-hep centru“ pruženo je ukupno **388** usluga savjetovanja i **121** usluga testiranja.

Bez obzira na izbor pristupa uslugama Info-hep centra, svim zainteresiranima za informacije o virusnim hepatitisima jamči se anonimnost i povjerljivost, a prije svega razumijevanje za njihove probleme.

Iz podatka o načinu pristupa korisnika Info-hep centru u 2011. godini, po popularnosti se i dalje ističe besplatni telefon, koji zajedno sa svim telefonskim pozivima čini 63% svih načina komunikacije.



Javnost je informirana o ovakvoj vrsti usluge putem web stranice www.hepatos.hr te plaćenim oglašavanjem u tiskovinama „Jutarnji list“, „Slobodna Dalmacija“, te u magazinu „Optimist“.



Edukacija djece i mladih

Hepatos već sedmu godinu za redom provodi edukaciju mladih – učenika završnih razreda srednjih škola Splitsko-dalmatinske i Zadarske županije. Tijekom 2011. godine održano je **13 predavanja** u srednjim školama na području ove dvije županije kojima je obuhvaćeno **355 učenika i njihovih 12 profesora**.

Predavanja su u Splitsko-dalmatinskoj županiji održana u suradnji s dr. Dianom Nonković, iz Službe za epidemiologiju Nastavnog zavoda za javno zdravstvo SDŽ, te u Zadarskoj županiji u suradnji s dr. Nadiom Cavenago Morović, voditeljicom Službe za školsku medicinu Zavoda za javno zdravstvo Zadar.

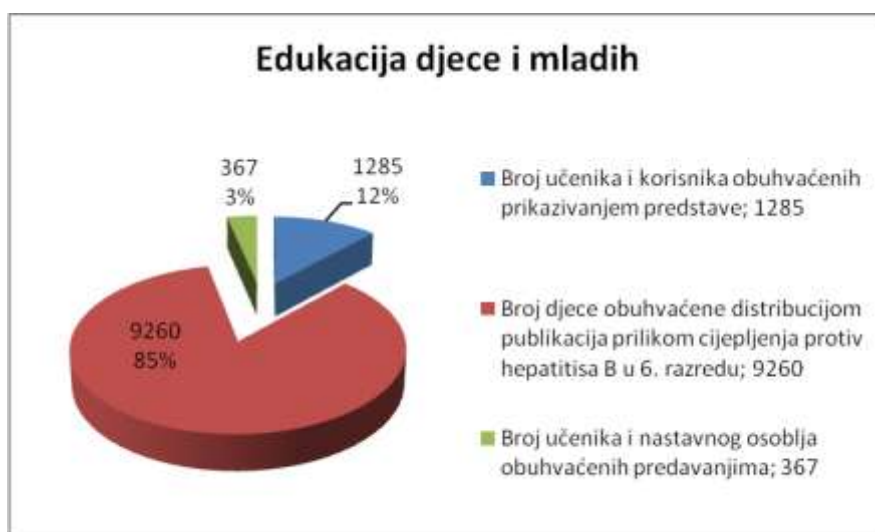
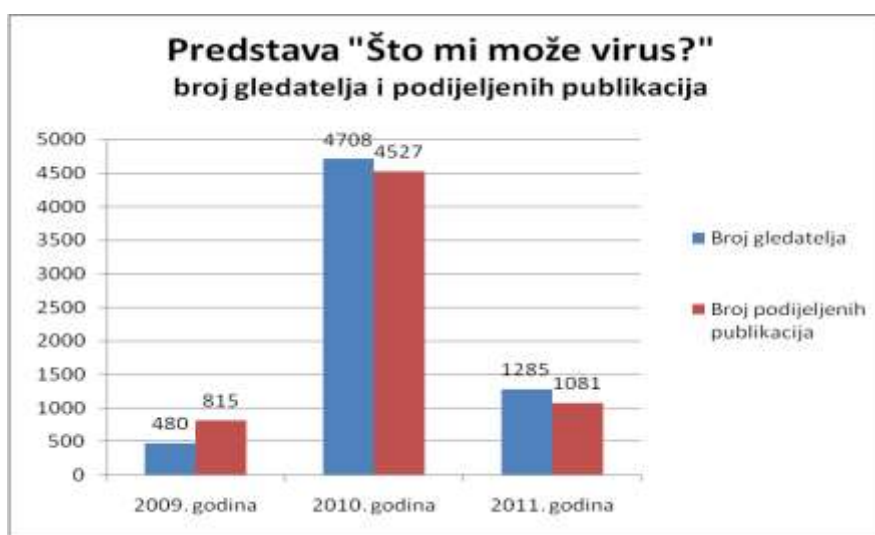


U suradnji sa Službom za školsku medicinu županijskih zavoda za javno zdravstvo podijelili smo brošure prilikom cijepljenja učenika šestih razreda osnovnih škola protiv hepatitisa B svim učenicima šestih razreda **Splitsko-dalmatinske, Šibensko-kninske, Zadarske**, a ove godine i **Ličko-senjske županije**.

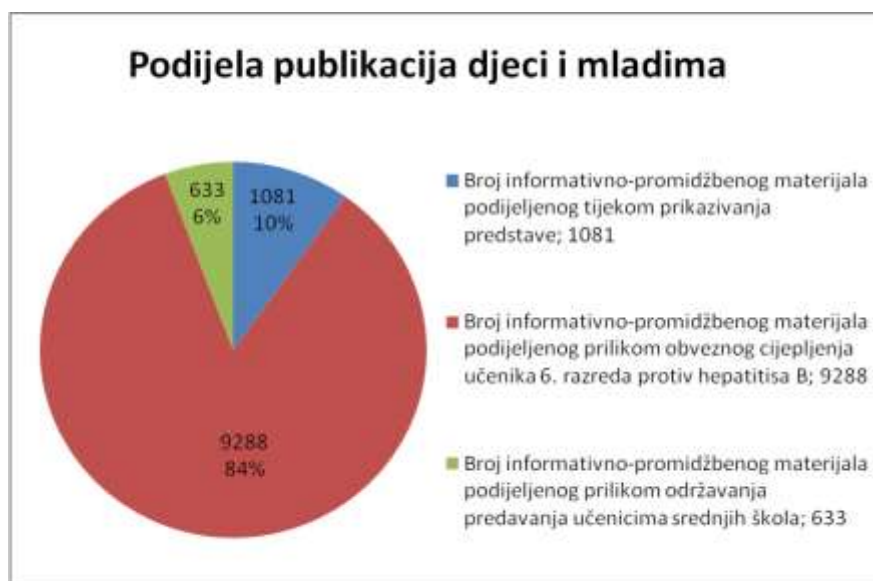
Ovom aktivnošću obuhvaćeno je ukupno **9 260 djece** iz sve četiri županije.



Edukativnu predstavu „Što mi može virus?“, koja je premijerno izvedena 17. 10. 2009. godine, tijekom 2011. godine pogledalo je **1 285 djece i mladih** iz osnovnih i srednjih škola Splitsko-dalmatinske i Koprivničko-križevačke županije. Predstavu je u posljednje tri godine pogledalo **6 473 gledatelja** širom Hrvatske i Bosne i Hercegovine.



Tijekom 2011. godine podijelili smo **18 196** informativno-promidžbenog materijala (brošure, letci, prospekti, bilteni, plakati, knjižne oznake...), od čega su **11 002** brošure podijeljene djeci i mladima.

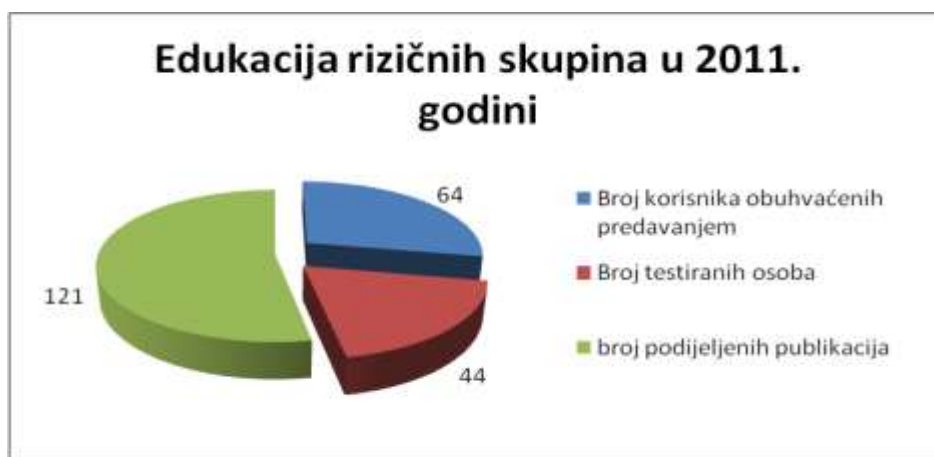


Edukacija rizičnih skupina

U suradnji s udrugama i terapijskim zajednicama koje se bave borbom protiv bolesti ovisnosti, Kaznenom ustanovom „Bilice“ iz Splita, dr. Dijanom Nonković iz Službe za epidemiologiju i dr. Magdom Pletikosa-Pavić iz Službe za zaštitu mentalnog zdravlja, prevenciju i izvanbolničko liječenje ovisnosti Nastavnog zavoda za javno zdravstvo Splitsko-dalmatinske županije, organizirali smo **4** informativna predavanja kojima su obuhvaćena ukupno **64 korisnika**. Predavanjima u Kaznenoj ustanovi „Bilice“ i dvjema terapijskim zajednicama obilježili smo Mjesec borbe protiv ovisnosti.

Tijekom predavanja, korisnicima su uz prikazivanje filma „Virus C“ podijeljene i informativno-edukativne publikacije, omogućeno testiranje na virusne hepatitise i HIV te pružanje psihosocijalne potpore.

Predavanja su u udrugama i terapijskim zajednicama koje se bave borbom protiv bolesti ovisnosti organizirana u sklopu projekta „Bez ovisnosti i bez hepatitisa“ kojeg je Udruga počela provoditi 2009. godine. Provedbom projekta doprinijeli smo povećanju motivacije ovisnika za mogućnost korištenja zdravstvenih i socijalnih ustanova, kroz ubrzanu proceduru obavljanja svih dijagnostičkih pretraga i prikupljanja potrebnih nalaza i/ili odobrenja od strane HZZO-a za uključivanje u liječenje kroničnog hepatitisa B i/ili C.



U cilju bolje suradnje s udrugama i terapijskim zajednicama koje okupljaju aktivne i bivše ovisnike srpnju 2011. godine **pristupili smo u novoosnovanoj Mreži organizacija civilnog društva "Zajedno protiv ovisnosti"**.

Predsjednica Hepatos mr. sc. Tatjana Reić sudjelovala je na **regionalnoj radionici o preventivnim programima** održanoj u **organizaciji Ureda za suzbijanje zlouporabe droga**, 24. svibnja 2011. godine. Na radionici je predstavljen projekt Baze preventivnih programa koja je ustrojena pri Uredu, Portal najboljih praksi EMCDDA i Nacionalni program prevencije ovisnosti za djecu i mlade u odgojno obrazovnom-sustavu te djecu i mlade u sustavu socijalne skrbi za razdoblje od 2012. do 2014. godine kojeg je donijela Vlada u lipnju 2010. godine.

Javno zagovaranje i lobiranje

Imenovanje Hepatos za National Focal Point za hepatitis za razdoblje 2010-2013, od strane Svjetske zdravstvene organizacije, kao prve organizacije civilnog društva uopće u RH, i to na preporuku Ministarstva zdravlja, potvrdilo je da je u području javnog zagovaranja Hepatos postigao razinu izvrsnosti te je stoga dragocjen izvor znanja i podrške drugim udrugama širom Europe, zapadnog Balkana i Hrvatske.

Hepatos je, od samog početka svog rada, konzistentan i glasan u svojem zahtjevu da se virusni hepatitis prepozna kao javnozdravstveni problem koji u rješavanju traži multidisciplinarni pristup, dakle suradnju između zdravstvenog sektora i ostalih područja javnog djelovanja, prvenstveno imajući na umu nevladin sektor, uz što više nezavisnih rasprava o zdravstvenoj skrbi oboljelih od virusnih hepatitisa.

U tu je svrhu u 2011. godini Hepatos inicirao **16 radnih sastanaka s predstavnicima sva 3 sektora**. Posebno ističemo

- ⇒ Sastanak s ravnateljem Uprave za zatvorski sustav Ministarstva pravosuđa RH mr. sc. Brankom Peranom, održanog 14. 12. 2011., čija je tema bilo potpisivanje Sporazuma o suradnji i planovi za 2012. godinu.

- ⇒ Sastanak sa pučkim pravobraniteljem Juricom Malčićem na temu jačanja kapaciteta institucije pučkog pravobranitelja, posebice kao središnjeg tijela nadležnog za suzbijanje diskriminacije, održanog u Splitu 11. 10. 2011. godine.
- ⇒ Slanje **otvorenog pisma** koje smo 29.06. 2011. uputili g.Tihomiru Strizrepu ravnatelju, i gđi. Renati Turčinov glasnogovornici Hrvatskog zavoda za zdravstveno osiguranje, s apelom za **uvršavanje lijeka Tenofovir na listu HZZO-a** za pacijente oboljele od kroničnog Hepatitisa B. Ovim dopisom željeli smo ukazati na činjenicu da hrvatskim pacijentima oboljelim od kroničnog hepatitisa B još uvijek nije dostupan najučinkovitiji nukleotid analog-Tenofovir, koji se u razvijenim zemljama smatra lijekom prvog izbora u liječenju ove bolesti.
- ⇒ Povodom obilježavanja Svjetskog dana hepatitisa uputili smo 501 dopisa s prigodnim informativno-edukativnim materijalima, svim saborskim zastupnicima, liječnicima gastroenterolozima i infektolozima, ravnateljima zavoda za javno zdravstvo i predstavnicima medija.

Na međunarodnom planu su predsjednica Hepatososa, koja je ujedno i predsjednica ELPA-e (European Liver Patients Association), mr. sc. Tatjana Reić i volonter udruge Dalibor Ružić, sudjelovali na 18 međunarodnih javno-zagovaračkih aktivnosti, od kojih izdvajamo:

- ⇒ **10-11. 02. 2011. London, Velika Britanija** - sudjelovanje na sastanku Upravnog odbora World Hepatitis Alliance-a.
- ⇒ **22.-25. 03. 2011. Stockholm, Švedska** - sudjelovanje na 1. godišnjem sastanku europske mreže za nadzor nad hepatitisom B i C (*1st Annual meeting of the European Network for Hepatitis B/C Surveillance*) u organizaciji ECDC-a (Europski centar za prevenciju i kontrolu zaraznih bolesti).
- ⇒ **29. 03. - 03. 04. 2011. Berlin, Njemačka** - sudjelovanje na međunarodnom kongresu International Liver Congress™ 2011 tijekom 46. godišnjeg sastanka European Association for the Study of the Liver (EASL).
- ⇒ **29. 03. - 03. 04. 2011. Berlin, Njemačka** - predsjednica udruge mr. sc. Tatjana Reić sudjelovala je **kao panelistica na okruglom stolu** „*Health burden of viral hepatitis after the WHO resolution: A CALL FOR ACTION!*“.
- ⇒ **18.-23. 10. 2011., Hong Kong** - predavanje i sudjelovanje na međunarodnoj radionici namjenjenoj udrugama pacijenata pod nazivom „*Concepts to conversation: Unlocking policy*“ / Koncepti za razgovor: Otključavanje politika.



⇒ **01.-11. 11. 2011., San Francisco, USA** - sudjelovanje na kongresu American Association for the Study of Liver Diseases - The Liver Meeting 2011. Ciljevi kongresa bili su jačanje kapaciteta i usavršavanje znanja tj. učenje i upoznavanje s novim postignućima iz područja hepatologije te održavanje postojećih i stvaranje novih kontakata s bitnim dionicima: stručnjacima, stavotvoriteljima i donosiocima odluka, predstavnicima farmaceutske i popratne industrije.



⇒ **16.-20. 11. 2011., Milano, Italija** - sudjelovanje na sastanku Technical Viral Hepatitis Prevention board (VHPB) pod Nazivom „Hepatitis B vaccination: A completed schedule...enough to control HBV lifelong?“ te godišnjem sastanku i proslavi 20. godišnjice uvođenja cijepljenja u Italiji pod nazivom „Towards the eliminaton of hepatitis B -celebrating 20 years of vaccination in Italy“. Predsjednica naše udruge sudjelovala je i na sastanku **savjeta VHPB-a i tom je prilikom izabrana za njegovu novu članicu**, čime je struka još jednom pokazala koliko prepoznaje napore koje udruge pacijenata ulažu u zajedničkoj borbi protiv virusnih hepatitisa. Članovi ovog tijela su vrhunski i svjetski priznati stručnjaci koji se bave problematikom virusnih hepatitisa.



⇒ **21.-23. 12. 2011., London** Sudjelovanje na sastanku Hepatitis B & C Public Policy Association pod nazivom: *The possibility of including viral hepatitis in the Millennium Development Goals.*

Predsjednica Hepatososa, koja je ujedno i predsjednica European Liver Patients Association(ELPA) sudjelovala je na svim sastancima Upravnog i Savjetodavnog odbora ove europske organizacije koja okuplja udruge pacijenata s bolestima jetre.

Također ističemo i sudjelovanje članova naše udruge na pet promocija biografije o Ivanu Gudelju „Hajdučka priča“ autora Blaža Duplančića. „Hajdučka priča“ prati život Ivana Gudelja, nekadašnjeg igrača Hajduka koji je svoju sjajnu karijeru morao naglo prekinuti zbog obolijevanja od hepatitisa B u 26. godini života.

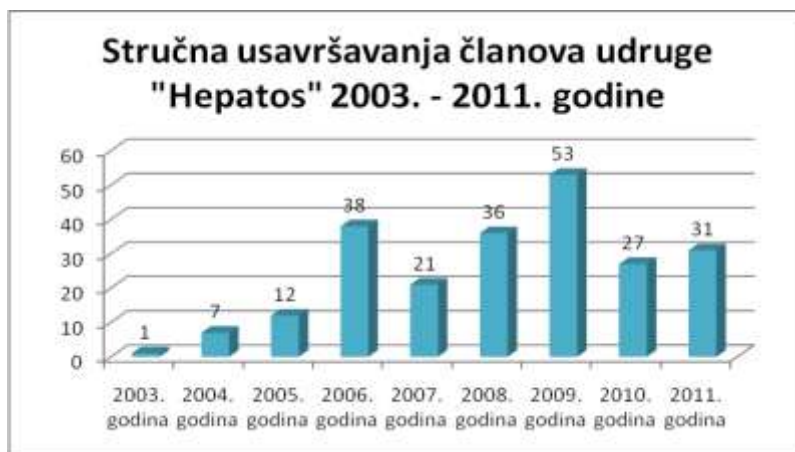
ORGANIZACIJSKA KLIMA I KAPACITETI

Redovni članovi udruge sudjelovali su tijekom 2011. godine na **31** različitoj radionici, konferenciji, stručnom predavanju i edukaciji, u svrhu stalnog jačanja ljudskih resursa i kapaciteta udruge, od kojih izdvajamo:

- radionice o financijskom poslovanju udruga (UTIRUŠ i KONTO OBAD)

- sudjelovanje na tri modula medijskog treninga (EDUCAmix)
- regionalna radionica o preventivnim programima u organizaciji Ureda za suzbijanje zlouporabe droga
- tečaj „Mediji i zdravlje: privatno i javno zdravstvo“ u okviru Motovunske ljetne škole unaprjeđenje zdravlja
- radionice na temu socijalnog/društvenog poduzetništva u okviru projekta SEFOR, projekta kojeg provodi Slap u suradnji s udrugama Zdravi grad, ACT (Autonomni Centar Čakovec) i CTK (Centar Tehničke Kulture Rijeka)
- brojni simpoziji i stručne radionice u sklopu međunarodnog kongresa International Liver Congress™ 2011 tijekom 46. godišnjeg sastanka European Association for the Study of the Liver (EASL) i međunarodnog kongresa The Liver Meeting 2011 u organizaciji American Association for the Study of the Liver Disease (AASLD)
- brojne međunarodne radionice poput "Optimising treatment access and outcomes among difficult-to-treat groups with hepatitis C and HIV/HCV coinfection" (European AIDS Treatment Group (EATG), Barcelona), „International Experience Exchange for Patient Organisations“ (Frankfurt), „HTA Patient Academy“ (European Forum Neurological Associations, London School of Economics), „Concepts to conversation: Unlocking policy“ (Hong Kong) i „The possibilities of the Digital Age: Advocacy 2.0“ (Brisel).





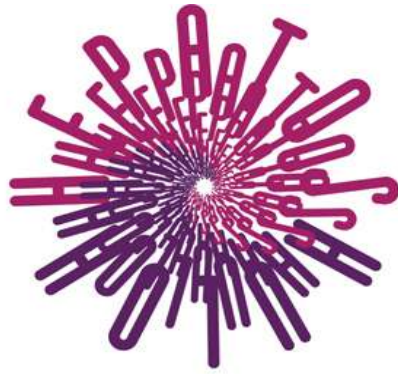
Zajedno s NVO Viktorija i Udruženjem „B18“ iz Banja Luke, Hepatos je zajedno aplicirao na natječaj IPA **prekogranični program Hrvatska – Bosna i Hercegovina 2007-2013**, u prioritetu Poboljšanje kvalitete života i socijalna kohezija, u mjeri Poboljšanje pristupa uslugama u lokalnoj zajednici u pograničnom području.

Uz kontinuirani organizacijski razvoj, posebice u području financijskog i projektnog upravljanja, Hepatos je nastavio s njegovanjem ali i širenjem svojih suradničkih odnosa s udrugama u Hrvatskoj ali i susjednim državama te u EU s kojima postoji podudarnost ali i komplementarnost područja djelovanja.

FINANCIJSKI IZVJEŠTAJ ZA 2011. GODINU

IZVORI PRIHODA u 2011. GODINI	HRK	EUR
Ministarstvo zdravstva i socijalne skrbi	196.677,50	26.119,19
Ministarstvo znanosti, obrazovanja i športa	69.551,07	9.236,53
Grad Split	22.026	2.925,10
Grad Zagreb	25.000	3.320,05
Splitsko-dalmatinska županija	10.000	1.328,02
Prihodi od inozemnih vlada i međunarodnih organizacija	138.703	18.420,05
Ostali prihodi od donacija	100.550	13.353,25
PRIHODI OD IMOVINE	17.158	2.278,62
PRIHODI OD PRUŽANJA USLUGA	49.476	6.570,52
OSTALI PRIHODI	29.812	3.959,10
UKUPNO	658.955	87.510,43

RASHODI U 2011. GODINI	HRK	EUR
Rashodi za radnike	146.573	19.465,21
Plaće za redovan rad	111.765	14.842,63
Ostali rashodi za radnike	16.600	2.204,52
Doprinosi za zdravstveno osiguranje	16.408	2.179,02
Doprinosi za zapošljavanje	1.800	239,04
Službena putovanja	73.955	9.821,38
Naknada za prijevoz, za rad na terenu	12.367	1.642,36
Naknade za obavljanje aktivnosti	10.000	1.328,02
Usluge telefona, pošte i prijevoza	26.341	3.498,14
Usluge tekućeg i investicijskog održavanja	934	124,04
Usluge promidžbe i informiranja	61.989	8.232,27
Komunalne usluge	1.153	153,12
Zakupnine i najamnine	10.583	1.405,44
Intelektualne i osobne usluge	5.051	670,78
Računalne usluge	8.751	1.162,15
Ostale usluge	16.655	2.211,82
Uredski materijal i ostali materijalni rashodi	43.936	5.834,79
Energija	3.398	451,26
Sitni inventar i auto gume	647	85,92
Premije osiguranja	2.191	290,97
Reprezentacija	2.321	308,23
Članarine	1.037	137,72
Rashodi amortizacije	25.621	3.402,52
Financijski rashodi	2.250	298,8
Rashodi za ostala porezna davanja	1.007	133,73
UKUPNO:	603.333	80.123,88



CATIH Hepatos

Croatian Association of Treated
and Ill with Hepatitis

Annual report

Croatian Association of Treated and Ill with Hepatitis „Hepatos“

for 2011

Croatian Association of Treated and Ill with Hepatitis “Hepatos”

Number of employees:

4

Executive team

Tatjana Reić

Marijana Spaija

Maja Mihovilović

Nera Grbić

Additional info about the association

www.hepatos.hr

Association Bulletin

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Introductory word

As the most important event in 2011, we would like to point out the election of President of Hepatos as the **new President of the European Liver Patients' Association (ELPA)**, the umbrella association of the European liver patients' associations, on the Annual General Meeting held in Berlin on 31st March 2011.

We will remember 2011 also by repeated designation of Hepatos as the **National Focal Point for Hepatitis C** by the WHO, for the period 2012-2013. CATIH Hepatos was the first association to receive such recognition in 2009 for the period 2010-2011, upon recommendation of the Ministry of Health.

Repeated designation of our association as the National Focal Point for Hepatitis is the best indicator of the extent to which Hepatos is recognized and acknowledged by both international and national expert community fighting against viral hepatitis. It is a result of 11 years of dedicated work on improving the quality of life and rendering direct help to the ill, preventive and public health actions, advocacy, lobbying and influencing the legislation in favour of the ill, contributing to democratization and antidiscrimination, and last but not least, building the capacities of our association.

It is a pleasure for us to announce that FibroScan[®] device is finally available in Croatia. FibroScan[®] is a device which measures the elasticity and the degree of liver damage in an entirely painless way. The device is now available in Croatia owing in great part to the engagement of Hepatos from 2 years ago when we presented the device at the 6th Croatian congress on infectious diseases with international participation. Two FibroScan[®] devices were procured in January 2011 and are available to the patients in 2 referral centres of the Ministry of Health.

At international level, we participated in numerous workshops and congresses, among which we point out **The Liver Meeting 2011 by the American Association for the Study of Liver Diseases (AASLD)**, held in San Francisco and the **Viral Hepatitis Prevention Board Advisory Meeting**, held in Milan, at which **MS Tatjana Reić was elected as a new member of VHPB's Board of Advisors**.

We would like to put special emphasis on the World Hepatitis Day 2011, which was marked **on 28th July as the first official World Hepatitis Day** supported by the World Health Organization. **The central event of the World Hepatitis Day marking in Croatia was the public action on the Zrće beach**, a popular beach among young people, situated near Novalja on the island of Pag.

The recognizability of our Association's work is also confirmed by multiple **invitations to attend the promotion of the biographical book about Ivan Gudelj**, a former Croatian footballer, which describes his battle with chronic hepatitis B. During 2011, Hepatos participated in five promotions of "Hajdučka priča" in Sinj, Imotski, Zagreb, Mostar and Makarska.

ACHIEVED RESULTS IN 2011

International activities and joint information and education campaign with SOH RH

The President of Hepatos, Tatjana Reić MS, was unanimously elected as the **new President of the European Liver Patients' Association (ELPA)** at the Annual General Meeting of the organization, held in Berlin on 31st March 2011. Tatjana Reić was proposed as a candidate by the former President of ELPA, Mrs. Nadine Piorkowsky, who had been running ELPA successfully for 4 years. All ELPA members accepted Tatjana's candidacy with pleasure.

This year we have marked the **first official WHO World Hepatitis Day, 28th July**. The date 28th July was established as the official World Hepatitis Day at the 63rd World Health Organization Assembly meeting, by adoption of the Resolution on viral hepatitis, on 21st May 2011. The theme of this year's World Hepatitis Day, marked within the campaign **"This is hepatitis..."**, was **"Hepatitis affects everyone, everywhere. Know it. Confront it."** Particular emphasis was put on great influence of this epidemic, importance of informing and necessity of using the obtained information in fight against stigma, which is guilty for such ignorance about this epidemic. Various activities for marking of the World Hepatitis Day had been organized in more than 70 countries, coordinated by the World Hepatitis Alliance (WHA), the umbrella organization of hepatitis patients' organizations with more than 130 member associations from 58 countries.

As a member of the World Hepatitis Alliance and in collaboration with other associations from the Croatian Alliance of Hepatitis Patients Associations (SOH RH), we have successfully performed a series of WHD activities throughout Croatia. Our WHD activities have been performed under the auspices of the WHO Regional office for Croatia, with support and participation of Ministry of Health and Social Welfare Referral centers for diagnostics and viral hepatitis treatment, including more than 40 physicians/professionals from Institutes of Public Health of Gospić, Split, Zadar, Rijeka, Ličko-senjska County prefect, town of Novalja, Red Cross and others.

As in the previous years, **we have sent 501 letters** containing appropriate informative and educational materials and an invitation to support the marking of the World Hepatitis Day and our work to all members of the parliament, gastroenterologists, infectologists, directors of Institutes of Public Health and representatives of the media.

On 1st July 2011 we participated in a **symposium about the World Hepatitis Day** at the Infectious Diseases Clinic "Dr. Fran Mihaljević" in Zagreb, at which a member of Hepatos held a lecture entitled "Hepatitis C – what to do with difficult to treat patients – how can ELPA (European Liver Patients' Association) help them?". Besides the lecture, Hepatos had a stand with educational-informational materials.



Info days on city squares were held on 28th July in Križevci and Đurđevac and on 29th July in Koprivnica, with dissemination of informational-educational materials and free testing for hepatitis C.

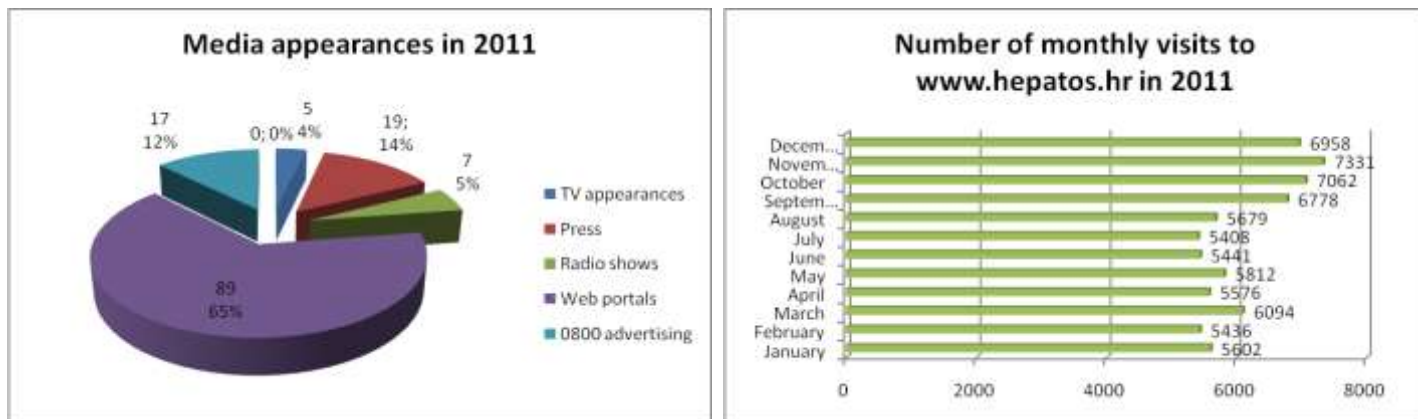
Among a total of **79 media appearances** anent marking of the **World Hepatitis Day**, on television, radio, web portals and press, we would like to put particular emphasis on the TV stories in the prime-time news shows of all TV stations with national coverage and the interviews and invitations broadcasted on as many as **19 radio stations** with local and/or national coverage.

On 28th July, the very World Hepatitis Day, we held the **central event of World Hepatitis Day marking in Croatia, the public action on the Zrće beach**. We have provided **counseling and free/anonymous testing for hepatitis C and HIV** to the beach visitors in the Red Cross tent. The result of the action is, besides 77 tested persons, increased awareness of the issue of viral hepatitis among the Croatian public, which was the main objective of the campaign.



All our activities are documented by news and photo-documentation on the web site www.hepatos.hr. In 2011, we published **40** association news and **163** translated news about the latest achievements in treatment and prevention of viral hepatitis.

In 2011, Hepatos had a total of **120** media appearances, among which we particularly point out the TV stories in the prime-time news shows of all TV stations with national coverage. During the year, our web site has been visited by **73 177** users, whom we have informed, educated and, if necessary, advised and directed, by means of email and on-line counseling.

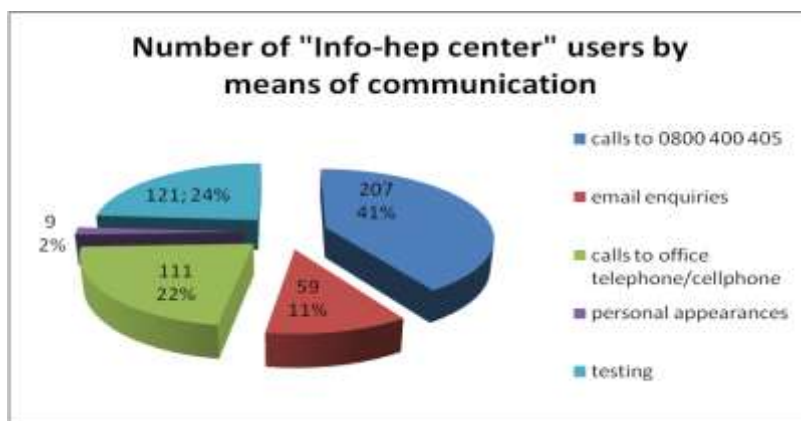


Providing support to hepatitis patients and their family members

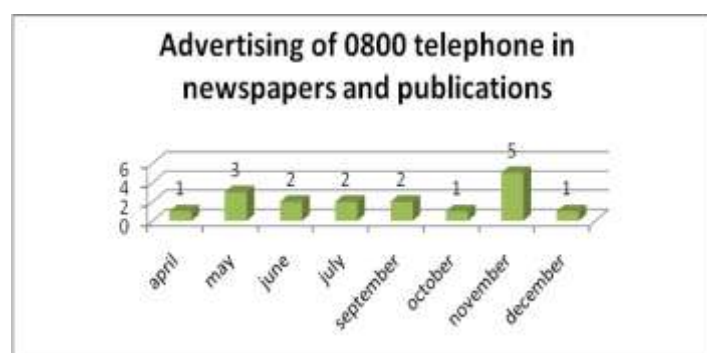
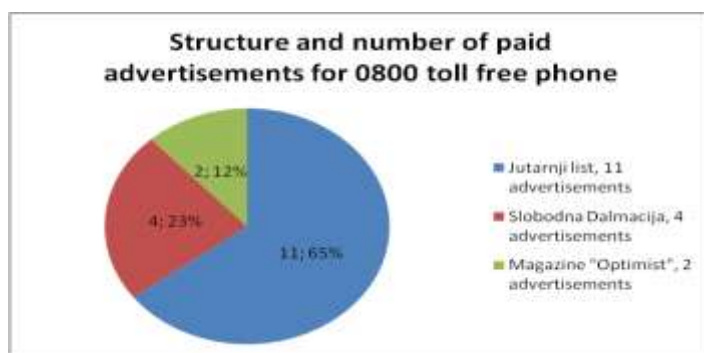
In accordance with the objectives of the Association which are defined by the Statute, the term "Info-hep Centre" defines our model for providing information about modes of transmission and consequences of viral hepatitis, health and psycho-social counseling on gaining access to treatment, and anonymous/free testing for viral hepatitis and HIV.

In 2011, we have provided almost **388** counselings and **121** testings in our "Info-hep Center". Appearing in person in our office, toll-free info telephone 0800 400405, "on-line counseling" with email enquiries, and distribution of informational-educational materials about the disease – no matter what approach to our services they might choose - privacy and anonymity is guaranteed to all persons interested in information about viral hepatitis, and above all, an appreciation of their problems.

From the data about means of approach to Info-hep Center in 2011, it is visible that the toll-free info telephone is still the most popular, which, together with the rest of phone calls makes up 63% of all ways of communication.



The public is informed about this kind of service through web site www.hepatos.hr and paid advertisements in newspapers and magazines such as "Jutarnji list", "Slobodna Dalmacija" and "Optimist".



Education of children and youth

For 7 years in a row Hepatos has been conducting education of the youth – the 3rd grade secondary school students of the Split-Dalmatia and Zadar Counties. During 2011, **13 lectures** had been held in secondary schools of the Split-Dalmatia and Zadar Counties, involving **355 students and 12 professors**.

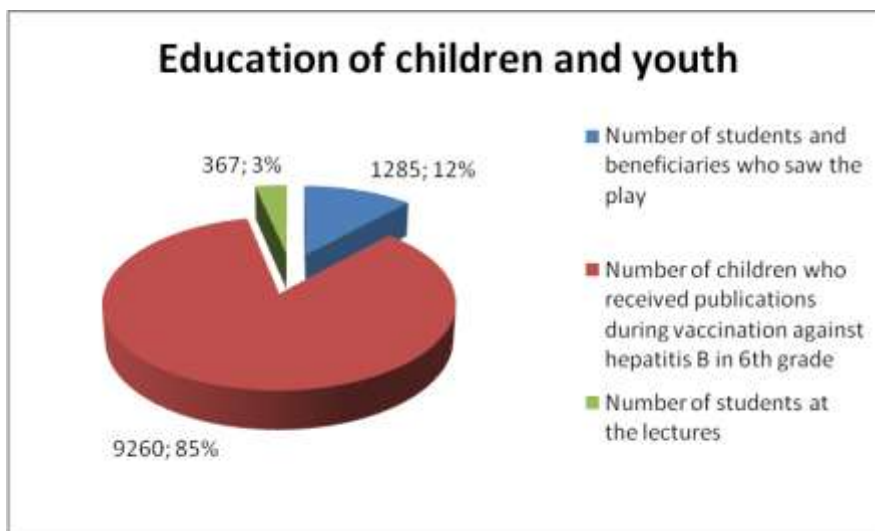
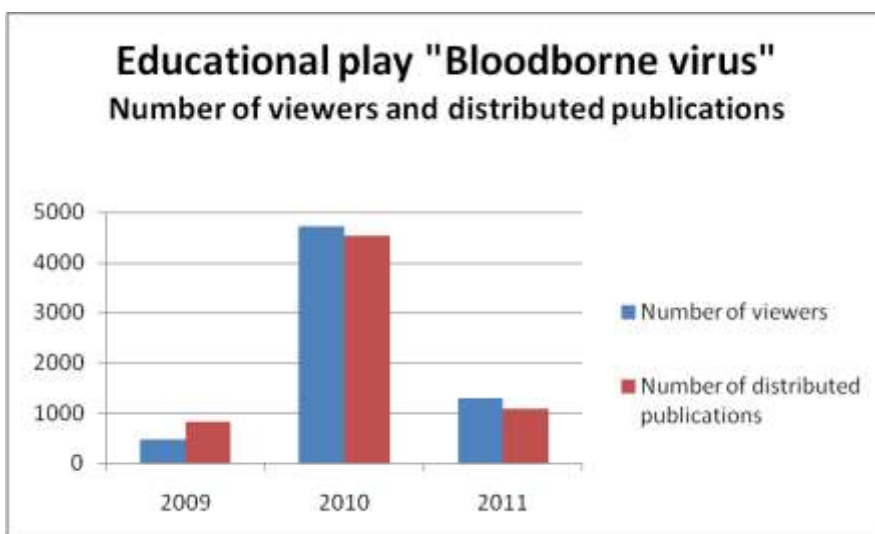
The lectures in the Split-Dalmatia County had been held in cooperation with dr. Diana Nonković from the Office for Mental Health Protection, Prevention and out-patient addiction treatment of the Public Health Institute of Split-Dalmatian County, while the lectures in the Zadar County had been performed by Dr. Nadia Cavenago Morović, the director of the School medicine service of the Institute of Public Health Zadar.



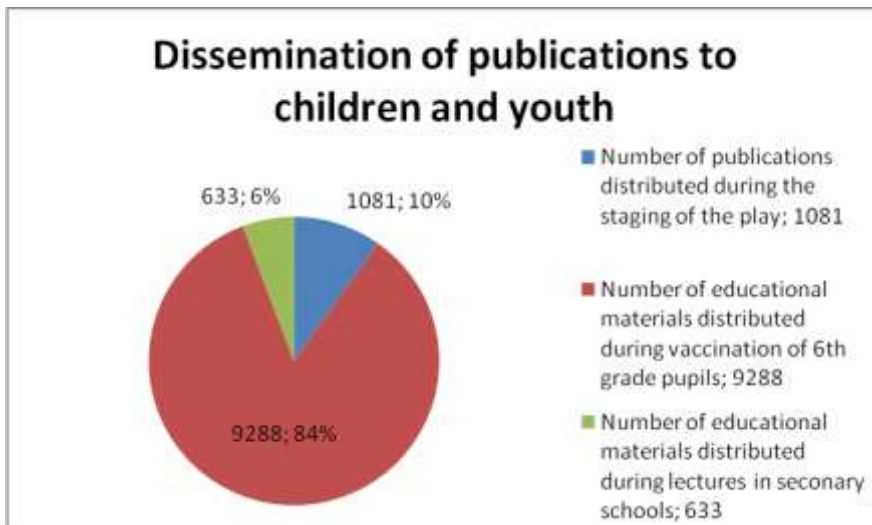
In cooperation with the School Medicine Services of the Counties' Institutes of Public Health, on occasion of vaccination of 6th grade students against hepatitis B, we have distributed brochures to all 6th grade students of the Split-Dalmatia, Šibenik-Knin, Zadar and Lika-Senj Counties. This activity encompassed a total of **9 260 children** from all four counties.



In 2011, **1285 children and youth** from elementary and secondary schools saw the educational play "Bloodborne virus" (original title: Što mi može virus?). The play was premiered on 17th October 2009, and since then it has been seen by **6 473 viewers** from Croatia and Bosnia Herzegovina.



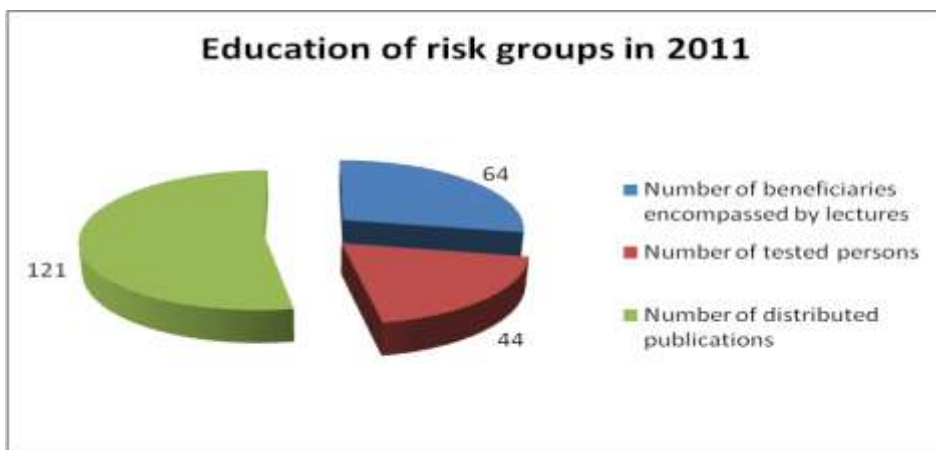
Over the course of 2011, we have distributed **18 196** informational and educational publications (brochures, flyers, prospects, bulletins, posters, etc.), **1 974** of which were distributed to secondary school students.



Education of the risk groups

In collaboration with **associations fighting against drug abuse**, Department of Infectious Diseases of the Split Clinical Hospital Center, Office for Mental Health Protection, Prevention and out-patient addiction treatment of the Public Health Institute of Split-Dalmatian County, and Bilice prison, we had organized **4** informational lectures which encompassed a total of **64 users**. The lectures in Bilice prison were organized on occasion of the International Day against Drug Abuse and Illicit Trafficking and the Drug abuse prevention month. During the lectures, we have shown an educational movie entitled “Virus C”, distributed informational-educational publications to the users and provided HCV/HIV testing and psychosocial support.

The lectures in associations fighting against drug abuse are organized within the project “Without addiction and without hepatitis” which has been conducted by Hepatos since 2009. Through this project we have motivated the drug addicts to explore the possibilities of using healthcare and social institutions, through an accelerated procedure of diagnosing and obtaining approval from HZZO-o for inclusion into treatment of chronic hepatitis B and C.



In order to establish better collaboration with associations fighting against drug abuse, Hepatos has joined the newly established **network of civil society organizations “Together against drug addiction”**.

The President of Hepatos, Tatjana Reic MS, took part in a **regional workshop on programmes of prevention organized by the Office for the prevention of drug abuse**, held on 24th May 2011. The workshop served as an occasion to present the Basis of prevention programmes which had been established within the Office, the Portal of best practices EMCDDA and the National program for prevention of drug addiction among children and youth in the educational system and youth in the social welfare system for the period 2012 – 2014, adopted by the Government of Croatia in June 2010.

Advocacy and lobbying

The designation of our association as the National Focal Point for Hepatitis 2010 – 2013 by the World Health Organization, as the first association to receive such recognition in Croatia, has confirmed once again that Hepatos has reached a high level of expertise in advocacy activities and it is therefore a valuable source of knowledge and support to other associations throughout Europe, western Balkans and Croatia.

From the very beginning of its work, Hepatos has been consistent and energetic in its demand that viral hepatitis be recognized as a public-health problem, which calls for a multidisciplinary approach in its solving, i.e. cooperation between the healthcare sector and other areas of public action, especially the non-governmental sector, with as many as possible independent discussions about health care for viral hepatitis patients.

For that purpose, in 2011, Hepatos had initiated **16 work meetings with the representatives of all 3 sectors**. We particularly emphasize:

- ⇒ The meeting with Mr. Branko Peran at the Central Office for Prison System held on 14th December 2011, at which we discussed signing of the collaboration agreement and the plans for 2012.
- ⇒ The meeting with ombudsman, Mr. Jurica Malčić, on strengthening capacities of ombudsmen as central bodies for prevention of discrimination, held in Split on 11th October 2011.
- ⇒ Sending of an **open letter** to the director and the spokesperson of the HZZO (Croatian Institute for Health Insurance), with the **appeal to include Tenofovir in the HZZO positive reimbursement list of drugs** for chronic hepatitis B patients. By means of this letter we wanted to point out to the fact that Croatian chronic hepatitis B patients still don't have access to the most effective nucleotide analogue which is considered as the first choice drug for treatment of chronic hepatitis B.
- ⇒ On the occasion of WHD commemoration, we have sent 501 letters containing appropriate informative and educational materials and an invitation to support the marking of the World Hepatitis Day and our

work to all members of the parliament, gastroenterologists and infectologists, directors of Institutes of Public Health and representatives of the media.

At international level, the President of Hepatos and ELPA, MS Tatjana Reic, and a volunteer of Hepatos, Dalibor Ružić, have participated in 18 international advocacy and lobbying activities during the course of 2011, among which:

- ⇒ **10-11 February 2011, London, United Kingdom** – participation in a meeting of the World Hepatitis Alliance Governing board.
- ⇒ **22-25 March 2011, Stockholm, Sweden** – participation in the 1st Annual meeting of the European Network for Hepatitis B/C Surveillance, organized by the European Centre for Disease Prevention and Control (ECDC).
- ⇒ **29 March – 3 April 2011, Berlin, Germany** – participation in the International Liver Congress™ 2011 during the 46th Annual meeting of the European Association for the Study of the Liver (EASL).
- ⇒ **29 March – 3 April 2011, Berlin, Germany** – The President of Hepatos, MS Tatjana Reic, participated in a round table discussion „*Health burden of viral hepatitis after the WHO resolution: A CALL FOR ACTION!*“.
- ⇒ **18–23 October 2011, Hong Kong** – Lecture and participation in an international workshop for patients' associations entitled „*Concepts to conversation: Unlocking policy*“.
- ⇒ **1-11 November 2011, San Francisco, USA** – participation in The Liver Meeting 2011, organized by the American Association for the Study of Liver Diseases. The objectives of participation were capacity building and broadening of knowledge. i.e. learning and acquainting with the most recent accomplishments in the field of hepatology, and maintaining existing and making new contacts with important stakeholders: experts, opinion makers, opinion leaders, representatives of the pharmaceutical and supporting industries.
- ⇒ **16-20 November 2011, Milan, Italy** – participation in a meeting of the Viral Hepatitis Prevention board (VHPB) entitled „*Hepatitis B vaccination: A completed schedule...enough to control HBV lifelong?*“,



the Annual meeting of the organization and celebration of the 20th anniversary of vaccination in Italy entitled „Towards the elimination of hepatitis B -celebrating 20 years of vaccination in Italy“. The President also took part in **the VHPB Advisers' meeting and was elected as a new member of that body**, which indicated once again that the profession recognizes the joint efforts put by patients' associations into fight against viral hepatitis. The VHPB advisors are excellent and globally recognized specialists from the field of viral hepatitis.

⇒ **21-23 December 2011, London, United Kingdom** – Participation in a meeting of Hepatitis B & C Public Policy Association entitled *“The possibility of including viral hepatitis in the Millennium Development Goals”*.

The President of Hepatos, MS Tatjana Reić, who is also the President of the European Liver Patients' Association (ELPA), participated in all meetings of Steering Committee and Advisory Board of this European umbrella association of liver patients' organizations.

We'd also like to mention participation of our members in 5 promotions of the biographical book about Ivan Gudelj *“Hajdučka priča”* (The Hajduk Story), written by Blaž Duplančić. The Hajduk story follows the life of Ivan Gudelj, a former player of the football club Hajduk, who had to discontinue his career at the age of 26 due to hepatitis B.

ORGANIZATIONAL CLIMATE AND CAPACITIES

During 2011 the regular members of Hepatos have participated in **31** different workshops, conferences, professional lectures and educations, with the purpose of continuous strengthening of our human resources. Some of the activities were:

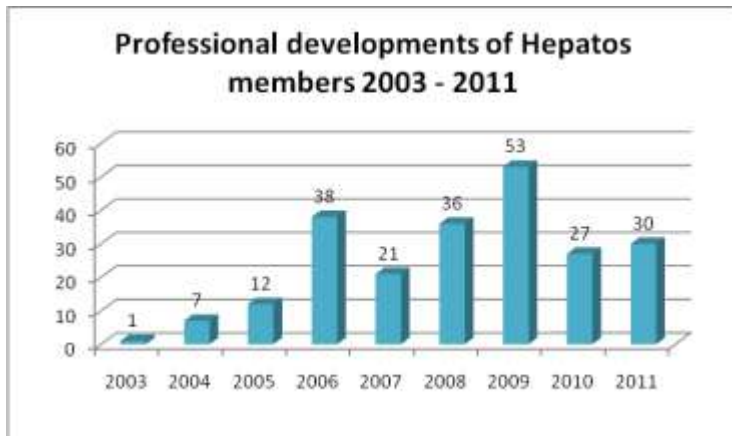
- Workshops on financial operations of NGOs (UTIRUŠ and KONTO OBAD)
- Participation in 3 modules of Media training (EDUCAmix)
- Regional workshop on prevention programs organized by the Office for the prevention of drug abuse
- Training course *“Media and health: private and public healthcare”* within the Motovun summer school of health improvement
- workshops on social entrepreneurship within the SEFOR project that is conducted by association *“Slap”* in collaboration with associations *“Zdravi grad”*, ACT and CTK
- Numerous symposia and expert workshops in conjunction with the International Liver Congress™ 2011 during the 46th Annual meeting of the EASL and the International Liver Meeting, organized by the AASLD.
- Numerous international workshops, such as *“Optimising treatment access and outcomes among difficult-to-treat groups with hepatitis C and HIV/HCV coinfection”* (Barcelona), *„International Experience Exchange for*

Patient Organisations“ (Frankfurt), „HTA Pacient Academy“ (London School of Economics), „Concepts to conversation: Unlocking policy“ (Hong Kong) and „The possibilities of the Digital Age: Advocacy 2.0“ (Brussels).



Hepatos has applied to **IPA Cross-border Programme between Croatia and Bosnia Herzegovina 2007 -2013** with a joint project with NGOs “Viktorija” and “B18” from Banja Luka, within the programe priority Improved Quality of Life and Social Cohesion, measure: Improving access to services in the local community in the border area.

With continuous organziational development, particularly in the field of financial and project management, Hepatos continues to cherish and broaden its collaborative relationships with associations from Croatia and the neighbouring countries, as well as with those from the EU, whose areas of interest coincide with or complement our.



FINANCIAL REPORT FOR 2011

INCOME SOURCES IN 2011	HRK	EURO
Ministry of Health and Social Welfare	196.677,50	26.119,19
Ministry of Science, Education and Sports	69.551,07	9.236,53
City of Split	22.026	2.925,10
City of Zagreb	25.000	3.320,05
Split-Dalmatia County	10.000	1.328,02
Income from foreign Governments and International Organizations	138.703	18.420,05
Other donations	100.550	13.353,25
INCOME FROM FINANCIAL ASSETS	17.158	2.278,62
INCOME FROM PROVIDING SERVICES	49.476	6.570,52
OTHER REVENUE	29.812	3.959,10
TOTAL	658.955	87.510,43

EXPENSES IN 2011	HRK	EURO
Expenses for employees	146.573	19.465,21
Netto earnings for employees	111.765	14.842,63
Other staff support	16.600	2.204,52
Health insurance taxes	16.408	2.179,02
Employment taxes	1.800	239,04
Official travel expenses	73.955	9.821,38
Transportation and field work expenses	12.367	1.642,36
Fees for performed activities	10.000	1.328,02
Telephone, postal and transportation services	26.341	3.498,14
Service maintenance	934	124,04
Promotion	61.989	8.232,27
Utilities	1.153	153,12
Lease and rent	10.583	1.405,44
Intellectual and personal services	5.051	670,78
IT services	8.751	1.162,15
Other services	16.655	2.211,82
Office supplies and other material expenses	43.936	5.834,79
Energy	3.398	451,26
Small inventory and car tyres	647	85,92
Insurance premium	2.191	290,97
Representation expenses	2.321	308,23
Memberships	1.037	137,72
Amortization	25.621	3.402,52
Financial expenses	2.250	298,8
Exchange difference and other expenses from confiscated long-term property	1.007	133,73
TOTAL:	603.333	80.123,88