ISSN 2712-472X

20 LET Z EUROTRANSPLANTOM

DAJ ŽIVLJENJU PRILOŽNOST

GIVE LIFE A CHANCE

DONORSKA IN TRANSPLANTACIJSKA DEJAVNOST V SLOVENIJI

DONATION AND TRANSPLANTATION ACTIVITY IN SLOVENIA

2019

DAJ
Življenju priložnost

Donorska in transplantacijska dejavnost
v Sloveniji v letu 2019

slovenija transplant

GIVE
Life a chance

Donation and transplantation activity
in Slovenia in 2019

Daj življenju priložnost - Donorska in transplantacijska dejavnost v Sloveniji v letu 2019

Urednici: Danica Avsec, Barbara Uštar

Avtorji: Barbara Uštar, Jana Šimenc, Andrej Gadžijev, Gorazd Čebulc, Jože Jakovac

Lektorica: Nives Mahne Čehovin

Oblikovanje in prelom: Vesna Žerjal

Tisk: Cicero Begunje, d.o.o.

Kraj in leto izida: Ljubljana, 2020

Založba: Zavod RS za presaditve organov in tkiv Slovenija-transplant

Avtorske pravice: Zavod RS za presaditve organov in tkiv Slovenija-transplant

Naklada: 250 izvodov

Publikacija je bila izdana s pomočjo javnih sredstev iz proračuna Zavoda RS za presaditve organov in tkiv Slovenija-transplant.

Publikacija je brezplačna.

ISSN 2712-472X

Give life a chance – Donation and transplantation activity in Slovenia in 2019

Editors: Danica Avsec, Barbara Uštar

Authors: Barbara Uštar, Jana Šimenc, Andrej Gadžijev, Gorazd Čebulc, Jože Jakovac

Translation: Nives Mahne Čehovin

Language editing and proofreading: Murray James Bales

Layout and design: Vesna Žerjal

Printed by: Cicero Begunje, d.o.o.

Slovenia: Ljubljana 2020

Original title: Daj življenju priložnost - Donorska in transplantacijska dejavnost v Sloveniji v letu 2019

Publisher: Institute for Transplantation of Organs and Tissues of the Republic of Slovenia Slovenija-transplant

Copyright: Institute for Transplantation of Organs and Tissues of the Republic of Slovenia Slovenija-transplant

Printed in 250 copies

This publication is funded from public funds – budget of Institute for Transplantation of Organs and Tissues of the Republic of Slovenia Slovenija-transplant.

This publication is free of charge.

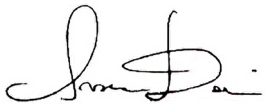
Uvodne besede

V letni publikaciji Daj življenju priložnost predstavljamo statistične podatke in izbrane presežke v donorski in transplantacijski dejavnosti v letu 2019. Podatki so pregledno umeščeni v mednarodni kontekst in širši časovni okvir, kar omogoča boljše razumevanje uspešnosti nacionalnih programov.

V preteklem letu vse države v Eurotransplantu beležimo rahle padce v donorskih in transplantacijskih programih. Reorganizacija v alokaciji organov je nepričakovano negativno vplivala na manjše države, kot je Slovenija. Upad je bil najbolj opazen v programu presaditve ledvic, a predvidoma bodo v začetku letu 2020 pomanjkljivosti v sistemu alokacije popravljene. Kljub temu pa imamo navdušujoče uspehe v programih presaditev pljuč in src. Prav tako se z 21,14 darovalca na milijon prebivalcev še vedno uvrščamo v zgornji vrh držav v posmrtnem donorskem programu.

Z vsakim primerom darovanja in presaditve vedno znova jasno uvidimo, da je zdravljenje s presaditvijo zelo kompleksna dejavnost, ki jo lahko zagotavljamo le s skupnim, uigranim in celovitim pristopom. Zahvaljujem se vsem donorskim centrom, transplantacijskim ekipam, vidnejšim in manj vidnim članom ter vsem darovalcem, ki so sodelovali in/ali sodelujejo v donorskem in prejemniškem nacionalnem programu.

Vabim vas k branju publikacije. Namenjena je najširši zainteresirani javnosti.



Prim. Danica Avsec, dr. med., svetnica,
direktorica zavoda Slovenija-transplant
in odgovorna zdravnica za donorsko dejavnost

Kazalo

Table of contents

Slovarček temeljnih izrazov

BOLNIŠNIČNA KRVNA BANKA: enota, ki v bolnišnici shranjuje in razdeljuje kri ter krvne komponente in opravlja predtransfuzijsko testiranje ter bolnišnične transfuzijske dejavnosti. Za zbiranje krvi torej ni pooblaščena.

BOLNIŠNIČNI TRANSPLANTACIJSKI KOORDINATOR: zakon določa način imenovanja, naloge bolnišničnih koordinatorjev in pravilnik o koordinatorjih. Naloge bolnišničnih transplantacijskih koordinatorjev so: organizacija in koordinacija dela na vseh področjih transplantacijske dejavnosti v bolnišnici, od odkrivanja možnih mrtvih darovalcev do organizacije in koordinacije odvzemov v bolnišnici ter pospeševanje programa pridobivanja organov in tkiv za presaditev. Delo opravljajo zdravniki specialisti, ki so pridobili dodatna znanja o vseh področjih transplantacijske dejavnosti v bolnišnici oz. donorskem centru.

CENTRALNI TRANSPLANTACIJSKI KOORDINATOR: zdravnik z dodatnimi znanji, ki organizira in koordinira transplantacijsko dejavnost od zaznave možnega darovalca do odvzema. Centralni transplantacijski koordinatorji so v pripravljenosti 24 ur na dan vse dni na leto.

ČAKALNI SEZNAM (PREJEMNIKOV): zbirka podatkov zaporedno vpisanih pacientov, ki čakajo na presaditev z namenom zdravljenja. Indikacije za presaditev so za vsak organ/tkivo/celico specifične.

DAROVALEC: oseba, ki daruje del telesa za namen zdravljenja, ne glede na to, ali do darovanje pride za časa življenja ali po njeni/njegovi smrti.

DAROVANJE: darovanje dela telesa, namenjenega za zdravljenje s presaditvijo.

DEJANSKI UMRLI DAROVALEC: aktiven darovalec, od katerega je bil presajen vsaj en organ.

DODELJEVANJE: postopek, po katerem se izbere najustreznejšega prejemnika.

DONORSKA BOLNIŠNICA ALI CENTER: javnozdravstveni zavod ali enota tega zavoda, ki izvaja dejavnost pridobivanja delov telesa za namen zdravljenja s presaditvijo.

HUD NEŽELEN DOGODEK: kateri koli neželen ali nepredviden dogodek v zvezi s katero koli stopnjo postopka darovanja do presaditve, ki lahko povzroči prenos nalezljive bolezni, smrt, ogrozi življenje, povzroči invalidnost ali nezmožnost za delo, katerega posledica je hospitalizacija ali obolevnost, ali ki podaljša hospitalizacijo ali obolevnost.

HUDA NEŽELENA REAKCIJA: nenameren odziv, vključno s pojavom prenosljive bolezni, pri živem darovalcu ali prejemniku, ki bi lahko bil povezan s katero koli stopnjo postopka od darovanja do presaditve, ki je smrten, smrtno nevaren, ki povzroča invalidnost ali nezmožnost za delo, ali katerega posledica je hospitalizacija ali obolevnost ali ki podaljša hospitalizacijo ali obolevnost.

INTENZIVNO ZDRAVLJENJE/INTENZIVNA NEGA: zdravljenje, ki zahteva hitro odzivno diagnostiko, terapijo, nego in stalni nadzor življenjskih funkcij bolnika ponavadi v enoti za intenzivno zdravljenje.

MOŽEN UMRLI/MRTVI DAROVALEC: oseba, katere klinično stanje kaže na verjetnost, da izpolnjuje merila za možgansko smrt.

NACIONALNA IDENTIFIKACIJSKA ŠTEVILKA DAROVALCA OZIROMA PREJEMNIKA: identifikacijska oznaka, ki jo v skladu z nacionalnim sistemom identifikacije darovalcu ali prejemniku dodeli Slovenija-transplant in služi kot povezovalni znak, prek katerega se sledi darovalcu in prejemniku organa, zlasti pri izmenjavi podatkov med donorskimi centri, transplantacijskimi centri in drugimi državami članicami Evropske unije.

PRIMEREN UMRLI/MRTVI DAROVALEC: medicinsko ustrezna oseba, pri kateri je bila ugotovljena smrt na podlagi nevroloških meril, glede na relevantno zakonodajo.

SLEDLJIVOST: možnost, da se najde in identificira organ v vseh fazah preskrbe z organi ali uničenja, vključno z možnostjo, da se identificirata darovalec in donorski center, poiščejo prejemniki pri transplantacijskem centru ter identificirajo vsi pomembni neosebni podatki v zvezi s proizvodi in materiali v stiku z organom.

STOPNJA ODKLONITVE: odstotek odklonitev svojcev oz. oseb, ki so blizu umrlemu, za darovanje po smrti.

STOPNJA ZAVRNITEV: odstotek zavrnitev presadka pri prejemniku.

TRANSPLANTACIJSKA DEJAVNOST: zdravstvena dejavnost, ki vključuje postopke darovanja, pridobivanja, testiranja in razdeljevanja organov ter darovanja, pridobivanja, testiranja, predelave, konzerviranja, shranjevanja in razdeljevanja tkiv in celic za potrebe zdravljenja s presaditvijo.

TRANSPLANTACIJSKI CENTER: javnozdravstveni zavod ali enota tega zavoda, ki izvaja dejavnost zdravljenja s presaditvijo organov.

TRANSFUZIJSKI CENTER: organizacijska enota, ki je v bolnišnici odgovorna za zbiranje krvi, testiranje, predelavo zbrane krvi v krvne komponente in njihovo shranjevanje. Izvaja predtransfuzijsko testiranje in bolnišnične transfuzijske dejavnosti ter bolnišnice in druge porabnike oskrbuje s krvjo in krvnimi komponentami.

TRANSFUZIJSKI ZAVOD OZIROMA ZAVOD RS ZA TRANSFUZIJSKO MEDICINO V LJUBLJANI: na državni ravni odgovoren za strokovno raven preskrbe s krvjo in krvnimi pripravki ter povezovanje transfuzijske medicine z bolnišnično dejavnostjo. Zavod usklajuje vse dejavnosti v zvezi z izbiro krvodajalcev, zbiranjem, testiranjem, predelavo, hrambo in razdeljevanjem krvi ter krvnih pripravkov, klinično rabo krvi in nadzorom nad težkimi neželenimi dogodki oziroma reakcijami v zvezi s transfuzijo krvi. Zavod RS za transfuzijsko medicino na državni ravni usklajuje in povezuje mrežo bolnišničnih transfuzijskih oddelkov in bolnišničnih krvnih bank, vodi enoten informacijski sistem, strokovno izobraževanje in razvojno-raziskovalno dejavnost ter sodeluje z mednarodnimi organizacijami, zvezami in sorodnimi zavodi v drugih državah.

Zavod Slovenija-transplant

Javni zavod Republike Slovenije za presaditve organov in tkiv Slovenija-transplant je od leta 2002 osrednja nacionalna strokovna ustanova, ki povezuje, koordinira, pospešuje ter nadzira donorsko in transplantacijsko dejavnost v Sloveniji. V zavodu Slovenija-transplant je centralna koordinacijska pisarna nacionalne transplantacijske mreže, ki je bila ustanovljena leta 1998. Nacionalno mrežo sestavlja enajst donorskih bolnišnic po Sloveniji, Center za transplantacijsko dejavnost v UKC Ljubljana in Center za tipizacijo tkiv, ki deluje v sklopu Zavoda RS za transfuzijsko medicino. Nacionalna mreža omogoča delovanje donorskega in prejemniškega programa ter zagotavlja, da imajo dostop do zdravljenja s presaditvijo vsi, ki ga potrebujejo. Mreža deluje nepretrgoma, zato so strokovne ekipe v pripravljenosti 24 ur na dan, vse dni v letu.

Od leta 2000 je Slovenija vključena v neprofitno organizacijo za izmenjavo organov in tkiv Eurotransplant. Z izpolnjevanjem zahtevnih vstopnih pogojev se je prva iz regije priključila veliki skupini petih uspešnih držav na področju zdravljenja s presaditvijo, t. j. Nemčiji, Avstriji, Belgiji, Luksemburgu in Nizozemski. Od leta 2002 je Slovenija-transplant nosilec pogodbe z Eurotransplantom. Eurotransplant danes združuje 8 držav in prek 137 milijonov prebivalcev, sedež ima v Leidnu na Nizozemskem. Članstvo je pomembno za naše bolnike, saj so se s priključitvijo bistveno izboljšale možnosti preživetja in izidi zdravljenja s presaditvijo, predvsem v visoko urgentnih, življenjsko ogrožajočih stanjih, kot sta akutna odpoved delovanja srca in jeter, ter v drugih posebnih primerih (npr. otroci, hipersenzibilizirani bolniki). S sodelovanjem so se tudi občutno zmanjšali čakalni seznami, nacionalni transplantacijski programi so se razmahnili, izvajati smo začeli kombinirane presaditve. Predvsem pa smo lahko omogočili optimalnejšo tkivno skladnost med darovalcem in prejemnikom. Nekateri bolniki zaradi tkivne neskladnosti ustreznega organa v Sloveniji sploh ne bi dočakali. V letu 2020 bomo z več dogodki obeležili pomembno 20. obletnico uspešnega sodelovanja z Eurotransplantom.

Zavod Slovenija-transplant se od ustanovitve naprej nenehno razvija v skladu s priporočenimi mednarodnimi smernicami. Stremimo k ustvarjanju izobražene in motivirane strokovne javnosti ter z večplastnim komuniciranjem vztrajno povečujemo zaupanje v transplantacijsko medicino med splošno javnostjo. Preko članstev v mednarodnih strokovnih odborih in s sodelovanjem v evropskih projektih smo tesno vpeti v mednarodno okolje, tudi kot aktivni soustvarjalci strategij, razvoja in izobraževanja strokovnjakov v donorski in transplantacijski dejavnosti na mednarodnem področju. Ostajamo mednarodno prepoznan in zgleden primer za način organizacije in vodenja nacionalnega donorskega programa.

Pri urejanju in vodenju področja pridobivanja in uporabe delov človeškega telesa za namen zdravljenja v Slovenija-transplantu dosledno upoštevamo zakonodajo, evropske direktive in sprejete mednarodne konvencije. Skrbimo za ustrezno posodabljanje nacionalne zakonodaje in strokovnih protokolov. Ob uvajanju sprememb vključujemo soglasno sprejete odločitve stroke, kritične družbene premisleke ter načela medicinske etike in deontologije.

Slovenija-transplant od ustanovitve vodi prim. Danica Avsec, dr. med, svetnica in odgovorna zdravnica za donorsko dejavnost. Zavod deluje pod okriljem Ministrstva RS za zdravje. V letu 2019 je bilo v organizaciji devet redno zaposlenih, v donorskem programu pa sta sodelovala 102 pogodbena sodelavca.

Ključne smernice delovanja zavoda so: samozadostnost | enakost in varnost za bolnike | optimalna učinkovitost | kakovost | sledljivost | profesionalnost | nekomercialnost | transparentnost | prostovoljno darovanje | preprečevanje zlorab.

www.slovenija-transplant.si
@SloTransplant

Presežki in zaznamki leta 2019

10.000 vpisanih v registru opredeljenih oseb

V nacionalnem registru opredeljenih oseb glede darovanja organov in tkiv po smrti je bilo konec leta vpisanih skoraj 10.000 ljudi. Že v prvih dneh januarja 2020 smo številko presegli. V začetku januarja je bilo tako opredeljenih 10.137 ljudi, kar je 0,57 % prebivalcev, starejših od 15 let. Tudi v letu 2020 bomo nadaljevali z aktivnostmi ozaveščanja javnosti in spodbujanjem k opredelitvi, s poudarkom na elektronski poti prek portala *www.e-uprava.si.* Možnost elektronske oddaje izjave za ali proti darovanju prek spletnega portala eUprava smo zaradi poenostavitve postopka vzpostavili v novembru 2018. Naslednje leto se je po tej poti opredelilo 566 oseb, kar predstavlja slabo polovico vseh podanih opredelitev v letu 2019.

Navdušujoči rezultati v nacionalnem programu za presaditev pljuč v UKC Ljubljana

V letu 2019 je odlična multidisciplinarna ekipa v nacionalnem programu zdravljenja s presaditvijo pljuč dosegla izjemne rezultate. Po lanskoletnem ponovnem zagonu programa v transplantacijskem centru UKC Ljubljana so uspešno opravili kar deset zahtevnih presaditev obeh pljučnih kril, v enem primeru pa je bila presaditev za slovenskega pediatričnega bolnika opravljena še v univerzitetni bolnišnici na Dunaju. V vseh primerih obravnavo bolnikov pred presaditvijo pljuč ter sledenje po njej venomer opravljajo na pristojnih oddelkih UKC Ljubljana. Vsem vpletenim čestitamo za vrhunsko opravljeno delo!

100-odstotno soglasje svojcev in 10 aktivnih darovalcev v UKC Maribor

Ekipa v donorski bolnišnici UKC Maribor je v letu 2019 s trinajstimi možnimi in desetimi aktivnimi darovalci nadaljevala z dobrim delom v nacionalni donorski mreži. Od osmih (dejanskih) darovalcev je bil presajen vsaj en organ. Nadpovprečno izstopajo tudi po 100-odstotni stopnji soglasja

svojcev umrlih za darovanje. Vsem sodelavkam in sodelavcem v donorskem programu se zahvaljujemo za zavzetost in čestitamo za kakovostno opravljeno delo!

Zaključen EU projekt EUDONORGAN

Jeseni 2019 smo uspešno zaključili sodelovanje v 3-letnem evropskem projektu EUDONORGAN *(Training and social awareness for increasing organ donation in the European Union and neighbouring countries)*, ki ga je s posebno pogodbo financirala Evropska komisija. Dosežen je bil namen projekta, to je spodbujanje pozitivnega odnosa družbe do darovanja organov, multidisciplinarno in regijsko povezovanje vseh deležnikov in primerjava dobrih praks. Zavod Slovenija-transplant je bil poleg organizacij iz Španije, Hrvaške in Italije ključen partner v projektu v aktivnostih izobraževanja zdravstvenega osebja in ozaveščanja splošne javnosti. V letu 2019 sta bila pod vodstvom Slovenija-transplanta organizirana interdisciplinarna simpozija o darovanju organov v Budimpešti in Stockholmu. Aktivno smo sodelovali tudi na osrednjem seminarju v Evropskem parlamentu v Bruslju pri naslavljanju političnih avtoritet. Pokazalo se je, kako pomembno je mednarodno povezovanje na področju spodbujanja darovanja organov. Skupne akcije namreč prinesejo bolj uporabne in vidne rezultate, čeprav je še vedno preveč samostojnih aktivnosti na lokalni ravni, katerih učinki se kasneje porazgubijo.

O donorski medicini na mednarodnem simpoziju intenzivne medicine

S tematskim sklopom o donorski medicini smo sodelavci Slovenija-transplanta sodelovali na 28. mednarodnem simpoziju intenzivne medicine, ki je potekal 1. junija na Bledu v organizaciji Slovenskega združenja za intenzivno medicino. S kolegi s Poljske in Hrvaške smo predstavili aktualne smernice dela, ključne ovire za transplantacijsko dejavnost v enotah intenzivne medicine in

možnosti za razvoj nacionalnega donorskega programa, med drugim s programom o darovanju po cirkulatorni smrti.

Izsledki raziskovalnega projekta Družbeni vidiki darovanja organov v praksi

Kje so zadržki za opredelitev za darovanje, kljub temu da prek 85 % ljudi izraža načelno podporo zdravljenju s presaditvijo? Kako spodbuditi javnost k aktivnemu opredeljevanju in govoru o darovanju organov? Kakšne strategije ozaveščanja javnosti so najuspešnejše? To so nekatera ključna vprašanja, na katera smo iskali odgovore v aplikativnem raziskovalnem projektu Družbeni vidiki darovanja organov (sofinancer ARRS), v sodelovanju s Fakulteto za družbene vede Univerze v Ljubljani in Nacionalnim inštitutom za varovanje zdravja. Opravljena je bila vseslovenska terenska raziskava o stališčih glede darovanja organov in pripravljena priporočila za komuniciranje z javnostmi (glej Berzelak, Avsec, Kamin 2019). Projekt smo uspešno zaključili, sveže raziskovalne izsledke in dognanja pa že vključujemo v komunikacijske aktivnosti.

Izobraževanje in certificiranje evropskih transplantacijskih koordinatorjev (CETC)

Prim. Danica Avsec je v vlogi predsednice mednarodnega odbora *Board of Transplant Coordinators* (BTC), ki deluje pod okriljem evropskega združenja *UEMS Surgery*, v sodelovanju s turško organizacijo *Turkish Transplant Foundation* organizirala pripravljalni tečaj na izpit za evropskega transplantacijskega koordinatorja (CETC). Tečaj za udeležence je potekal 1. in 2. avgusta 2019 v Istanbulu. Kot predavatelja sta sodelovala prim. Danica Avsec in Andrej Gadžijev. Tečaja sta se med drugim udeležili dve slovenski kandidatki za izpit CETC in ga kasneje z odliko tudi opravili. Izpit je potekal 14. septembra v Københavnu pod okriljem kongresa Evropskega združenja za transplantacijo organov (ESOT).

O etičnih vprašanjih v transplantacijski medicini

7. junija je v prostorih UKC Ljubljana potekal mednarodni simpozij Etični izzivi pri transplantaciji organov. Na simpoziju so bile izpostavljene marsikatere slabe prakse iz tujine. Z referati prim. Danice Avsec in Andreja Gadžijeva smo pojasnili prednostna področja Slovenija-transplanta, tudi etične osnove in smernice, na katerih delujemo na področju boja proti trgovanju in uvajanju sprememb v donorskih programih. Prikazali smo, kako je z dobro organizacijo in s spoštovanjem visokih etičnih meril možno zagotoviti varno, kakovostno in transparentno transplantacijsko zdravljenje. Kakršnekoli zlorabe sistema so namreč pri nas izključene in so kazensko preganjane. Prim. Avsec tudi aktivno sodeluje v mednarodnih telesih in s tem prispeva k pregonu nedopustnih kršenj človekovih pravic v obliki trgovine z organi in k bolj etični drži v globalni transplantacijski skupnosti.

Ključne številke leta **2019**

NA ČAKALNEM SEZNAMU je bilo na dan 31. 12. 2019 **skupaj 156 bolnikov:**

- za srce **42**,
- za ledvico **95** (od tega 1 v kombinaciji z jetri in 1 v kombinaciji s trebušno slinavko),
- za presaditev jeter **17** (od tega 1 v kombinaciji z ledvico),
- trebušne slinavke **1** (v kombinaciji z ledvico).

V CENTRU ZA TRANSPLANTACIJSKO DEJAVNOST V UKC LJUBLJANA SO PRESADILI 95 ORGANOV:

- **38 ledvic,**
- **22 src,**
- **24 jeter,**
- **10 pljuč** in
- **1 trebušno slinavko**.

POVPREČNE ČAKALNE DOBE:

- za srce 247 dni (za urgentne presaditve 50 dni);
- za ledvico približno 300 dni;
- za jetra 254 dni.

V NACIONALNI REGISTER opredeljenih oseb se je vpisalo **1254 ljudi** (od tega 9 proti).

Aktivnih umrlih darovalcev je bilo 44, dejanskih umrlih darovalcev pa **38**, od katerih **SMO PRIDOBILI 132 ORGANOV.**

STOPNJA PRIVOLITVE svojcev za darovanje je bila visoka, **in sicer 78 %**. Podatek kaže na visoko podporo javnosti.

Čvrsti organi

NACIONALNI ČAKALNI SEZNAM ZA PRESADITVE ORGANOV

Čakalni seznam je seznam bolnikov, ki čakajo na del človeškega telesa za presaditev z namenom zdravljenja. Indikacije za presaditev so za vsak organ/tkivo/celico specifične. Vsi bolniki v Republiki Sloveniji imajo enake možnosti za uvrstitev na čakalni seznam prejemnikov in zagotovljen enak dostop do presaditve delov človeškega telesa. Konec leta 2019 je na presaditev organa čakalo 156 bolnikov, kar je največ do sedaj, predvsem na račun ponovnega zvišanja števila čakajočih na presaditev ledvice, ki se je v dveh letih skoraj podvojilo. Povprečna čakalna doba je za vse organe v primerjavi z ostalimi državami relativno kratka. Slovenski bolniki čakajo na presaditev srca, jeter ali ledvice v povprečju manj kot leto dni.

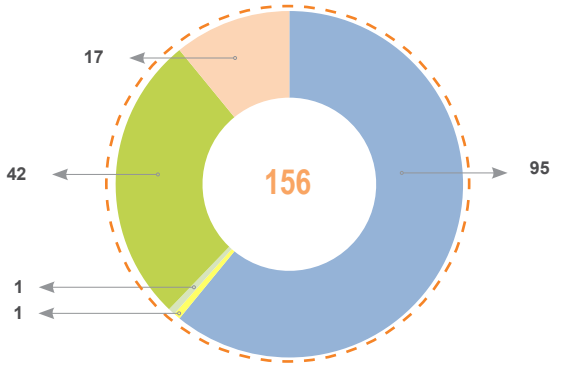
V letu 2019 je bilo v Sloveniji na čakalni seznam na novo uvrščenih 134 bolnikov, od tega 80 za ledvico, 27 za srce in 27 za jetra.

Stanje na nacionalnem čakalnem seznamu na dan 31. 12. 2019 (aktivni čakajoči)

Ledvica	Ledvica in trebušna slinavka	Ledvica in jetra	Srce
95	1	1	42
Srce in jetra	**Srce in ledvica**	**Jetra**	**Trebušna slinavka**
0	0	17	0
SKUPAJ			**156 bolnikov**

Vir: http://statistics.eurotransplant.org/

Delež bolnikov na nacionalnem čakalnem seznamu po posameznem organu oz. kombinaciji organov v letu 2019

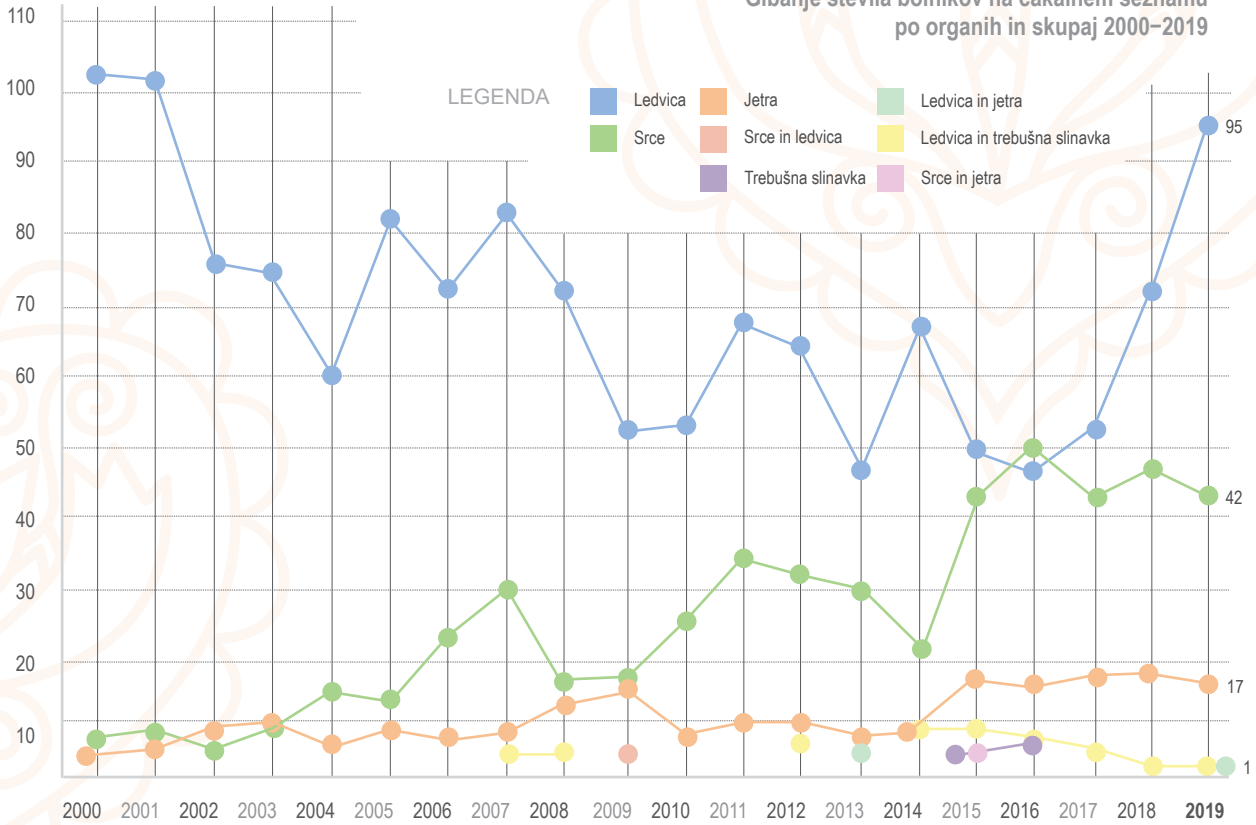


Nacionalni čakalni seznam v obdobju 2000–2019 (stanje na dan 31. 12., aktivni čakajoči)

Leto	Ledvica	Ledvica in trebušna slinavka	Ledvica in jetra	Srce	Srce in jetra	Srce in ledvica	Jetra	Trebušna slinavka	SKUPAJ
2000	102			7			2		**111**
2001	101			8			4		**113**
2002	76			2			7		**85**
2003	75			9			8		**92**
2004	60			15			4		**79**
2005	81			14			9		**104**
2006	72			24			6		**102**
2007	83	1		30			9		**123**
2008	71	1		17			13		**102**
2009	52			18		1	15		**86**
2010	53			26			8		**87**
2011	68			34			10		**112**
2012	65	2		32			10		**109**
2013	47		1	30			7		**85**
2014	69	8		21			9		**107**
2015	50	8		42	1		18	1	**120**
2016	47	3		50			17	2	**119**
2017	51	2		42			18		**113**
2018	72	1		48			19		**140**
2019	95	1	1	42			17		**156**

Vir: http://statistics.eurotransplant.org/

Gibanje števila bolnikov na čakalnem seznamu po organih in skupaj 2000–2019



ŠTEVILO UMRLIH DAROVALCEV

V letu 2019 smo v slovenskih donorskih bolnišnicah pridobili 44 aktivnih umrlih darovalcev*, ki so bili medicinsko ustrezni in za katere smo pridobili privolitev svojcev. Uvodoma so prikazani podatki o številu aktivnih umrlih darovalcev v Sloveniji v primerjavi z ostalimi državami sveta. V nadaljevanju so prikazani podatki o številu dejanskih umrlih darovalcev*, kar pomeni, da je bil od vsakega darovalca presajen vsaj en organ. V primerjavi z ostalimi državami članicami Eurotransplanta se Slovenija po številu dejanskih umrlih darovalcev na milijon prebivalcev v letu 2019 ponovno, kot že nekaj let zapored, uvršča na četrto mesto.

Število aktivnih umrlih darovalcev (MD) na milijon prebivalcev (NMP) v Sloveniji v letu 2019 v primerjavi z ostalimi državami sveta

Država	Število MD/NMP 2019
1. Španija	48,9
2. ZDA	36,88
3. Hrvaška	34,63
4. Portugalska*	33,63
5. Francija	33,25
6. Belgija	30,4
7. Češka	27
8. Finska	26,36
9. Belorusija	26,2
10. Malta*	25

Država	Število MD/NMP 2019
11. Anglija	24,88
12. Italija	24,7
13. Austrija	23,8
14. Urugvaj	22,86
15. Avstralija*	22,17
16.Slovenija	21,14
17. *Kanada**	20,56
18. Argentina*	19,6
19. Islandija	19,29
20. Švedska	19

Država	Število MD/NMP 2019
21. Estonija	18,8
22. Norveška	18,78
23. Litva	18,7
24. Madžarska	18,42
25. Švica	18,4
26. Irska	17,35
27. Danska	17,25
28. Brazilija*	16,73
29. Nizozemska	14,93
30. Slovaška*	14,35

*Podatki za leto 2018, **Število dejanskih darovalcev

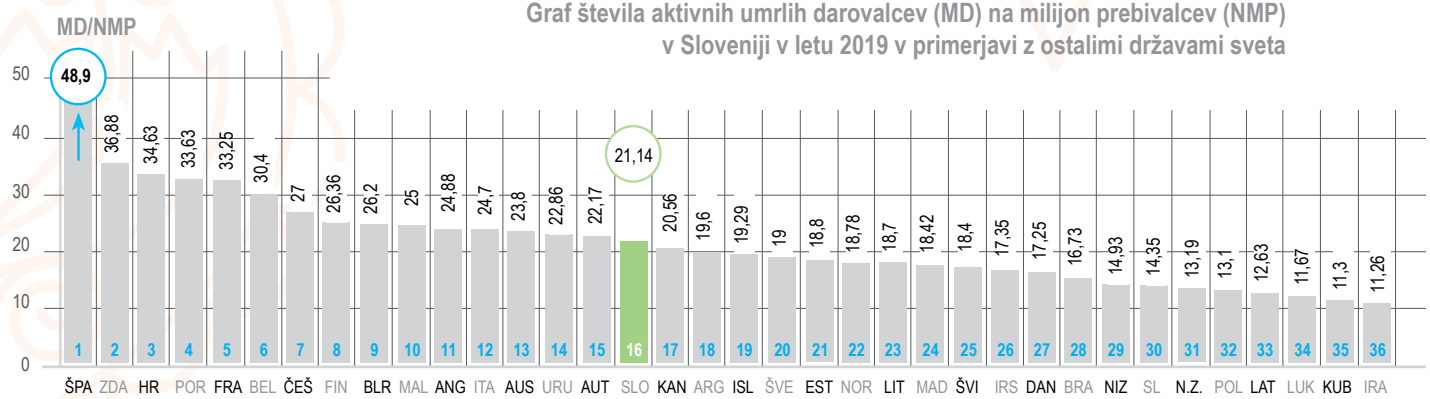
Država	Število MD/NMP 2019
31. Nova Zelandija*	13,19
32. Poljska	13,1
33. Latvija*	12,63
34. Luksenburg*	11,67
35. Kuba*	11,3
36. Iran*	11,26
37. Nemčija	11,2

Država	Število MD/NMP 2019
38. Izrael	10,8
39. Čile	10,4
40. Južna Koreja	8,68
41. Kolumbija*	8,04
42. Ekvador*	7,87
43. Turčija	7,54
44. Kostarika*	7

Država	Število MD/NMP 2019
45. Ciper	6,86
46. Kuvajt	6,75
47. Grčija	5,5
48. Rusija*	4,49
49. Kitajska*	4,43
50. Mehika*	4,39
51. Moldavija	4,1

*Podatki za leto 2018

Graf števila aktivnih umrlih darovalcev (MD) na milijon prebivalcev (NMP) v Sloveniji v letu 2019 v primerjavi z ostalimi državami sveta



Država	Število MD/NMP 2019
52. Hong Kong	3,86
53. Savdska Arabija	3,77
54. Bolgarija	3,71
55. Tajska	3,66
56. Romunija*	3,32
57. Katar*	2,59
58. Peru	2,3

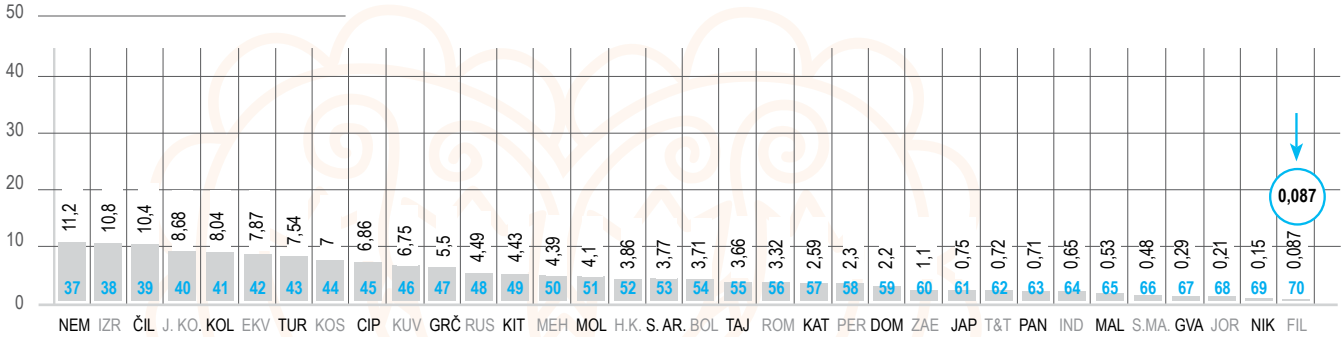
Država	Število MD/NMP 2019
59. Dominik. republika	2,2
60. ZAE*	1,1
61. Japonska*	0,75
62. Trinidad in Tobago*	0,72
63. Panama*	0,71
64. Indija*	0,65
65. Malezija	0,53

Država	Število MD/NMP 2019
66. Severna Makedonija*	0,48
67. Gvatemala*	0,29
68. Jordanija*	0,21
69. Nikaragva*	0,15
70. Filipini	0,087

*Podatki za leto 2018

Vir: IRODaT (International Registry in Organ Donation and Transplantation), www.irodat.org, Preliminary numbers 2019

MD/NMP

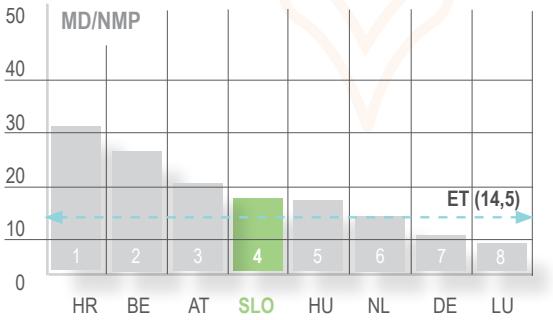


Število dejanskih umrlih darovalcev (MD) na milijon prebivalcev (NMP) v Sloveniji v letu 2019 in v primerjavi z državami Eurotransplanta.

Država	Slovenija (SLO)	Eurotransplant (ET)
Število MD	38	2.042
MD/PMP	18,3	14,5

Število dejanskih umrlih darovalcev na milijon prebivalcev (MD/NMP) ter primerjava z državami Eurotransplanta v letu 2019

Država ET	Število MD/NMP 2019
1. Hrvaška (HR)	31,4
2. Belgija (BE)	27,2
3. Avstrija (AT)	20,3
4. Slovenija (SLO)	18,3
5. Madžarska (HU)	18,2
6. Nizozemska (NL)	14,5
7. Nemčija (DE)	10,8
8. Luksemburg (LU)	8,1



Vir: http://statistics.eurotransplant.org/

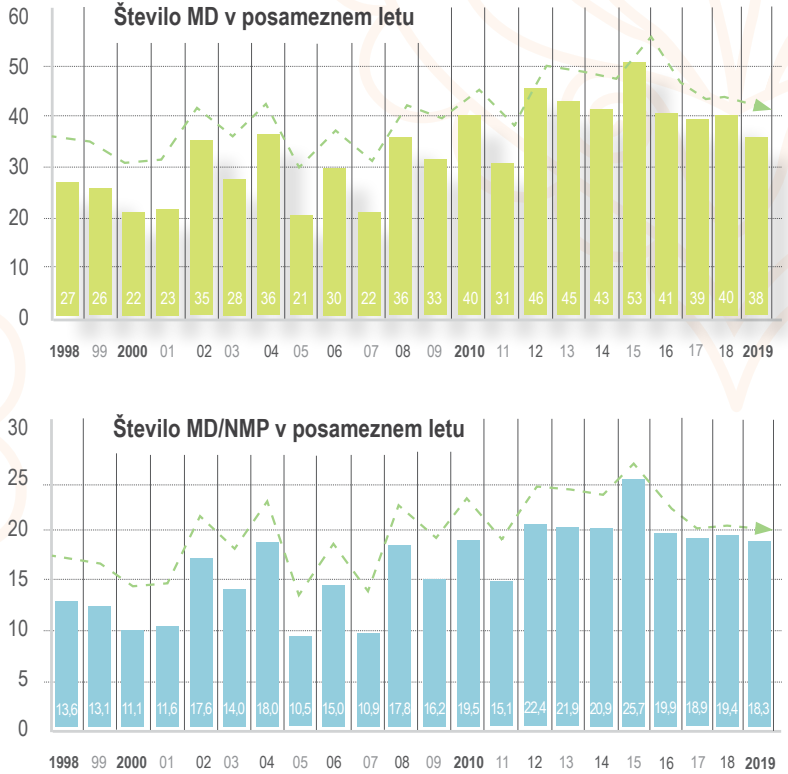
Število dejanskih umrlih darovalcev (MD) ter število umrlih darovalcev na milijon prebivalcev (MD/NMP) Sloveniji v letih od 1998 do 2019

Leto	Število MD	Število MD/NMP
1998	27	13,6
1999	26	13,1
2000	22	11,1
2001	23	11,6
2002	35	17,6
2003	28	14
2004	36	18
2005	21	10,5
2006	30	15
2007	22	10,9
2008	36	17,8
2009	33	16,2
2010	40	19,5

Leto	Število MD	Število MD/NMP
2011	31	15,1
2012	46	22,4
2013	45	21,9
2014	43	20,9
2015	53	25,7
2016	41	19,9
2017	39	18,9
2018	40	19,4
2019	38	18,3
SKUPAJ	755	16,9

Vir: http://statistics.eurotransplant.org/

Grafični prikaz števila dejanskih umrlih darovalcev (MD) in število dejanskih umrlih darovalcev na milijon prebivalcev (MD/NMP) v Sloveniji v letih od 1998 do 2019



* Klasifikacija umrlih darovalcev organov

<table>
<tr><th colspan="3">MOREBITEN UMRLI DAROVALEC ORGANOV
Bolnik s hudo poškodbo možganov ALI bolnik z zaustavitvijo krvnega obtoka IN očitno medicinsko primeren za darovanje organov</th></tr>
<tr><th>Darovanje po smrti zaradi zaustavitve krvnega obtoka (DSK)</th><th>Lečeči zdravnik prepozna/opozori na možnega darovalca</th><th>Darovanje po možganski smrti (DMS)</th></tr>
<tr><td>MOŽEN DAROVALEC (DSK)

a. Oseba, pri kateri se je zaustavilo delovanje krvnega obtoka in dihanje, postopki oživljanja se ne uporabijo oz. se ne nadaljujejo. ALI
b. Oseba, pri kateri je mogoče predvideti, da se bo v določenem časovnem okviru zaustavilo delovanje krvnega obtoka in dihanje, kar bo omogočilo pridobitev organov.</td><td rowspan="4">Razlogi, zakaj možen darovalec ne postane dejanski darovalec

SISTEM DELA
- Zdravstveno osebje ni prepoznalo /opozorilo na možnega mrtvega darovalca ali primernega darovalca,
- Možganska smrt ni potrjena (npr. ne izpolnjuje meril) oz. postopek ugotavljanja MS ni zaključen (npr. ker ni na voljo ustreznih diagnostičnih naprav oz. osebja, ki bi opravilo potrditveni test),
- Smrt zaradi zaustavitve krvnega obtoka ni pravočasno potrjena,
- Logistične težave (npr. ekipa za odvzem organov ni na voljo),
- Ni ustreznega prejemnika (npr. pri otroku, krvna skupina, pozitivna serologija).

DAROVALEC/ORGAN
- Medicinsko neustrezen (npr. pozitivna serologija, tumor),
- Hemodinamska nestabilnost /nepredvidena zaustavitev srca,
- Anatomske, histološke in/ali funkcionalne nepravilnosti organov,
- Organi poškodovani med postopkom pridobivanja,
- Nezadostna perfuzija organov ali krvni strdek.

PRIVOLITEV
- Umrli je za časa življenja izrazil voljo, da ne želi biti darovalec,
- Zavrnitev svojcev umrlega,
- Zavrnitev mrliškega oglednika ali preiskovalnega sodnika zaradi forenzičnih razlogov.</td><td>MOŽEN DAROVALEC (DMS)

Oseba, katere klinično stanje kaže na verjetnost, da izpolnjuje merila za možgansko smrt.</td></tr>
<tr><td>PRIMEREN DAROVALEC (DSK)

Medicinsko ustrezna oseba, pri kateri je bila ugotovljena smrt na podlagi nepovratne prekinitve delovanja krvnega obtoka in dihanja, glede na relevantno zakonodajo, v časovnem okviru, ki omogoča pridobitev organov.</td><td>PRIMEREN DAROVALEC (DMS)

Medicinsko ustrezna oseba, pri kateri je bila ugotovljena smrt na podlagi nevroloških meril, glede na relevantno zakonodajo.</td></tr>
<tr><td>AKTIVEN DAROVALEC (DSK)

Primeren darovalec, za katerega imamo privolitev
a. Narejen je bil operacijski rez z namenom pridobitve organov za namen presaditve. ALI
b. Pridobljen je bil vsaj en organ za namen presaditve.</td><td>AKTIVEN DAROVALEC (DMS)

Primeren darovalec,
za katerega imamo privolitev
a. Narejen je bil operacijski rez z namenom pridobitve organov za namen presaditve. ALI
b. Pridobljen je bil vsaj en organ za namen presaditve.</td></tr>
<tr><td>DEJANSKI DAROVALEC (DSK)

Aktiven darovalec, od katerega je bil presajen vsaj en organ.</td><td>DEJANSKI DAROVALEC (DMS)

Aktiven darovalec, od katerega je bil presajen vsaj en organ.</td></tr>
<tr><td colspan="3">Upoštevati je potrebno »pravilo umrlega darovalca«. Bolnik lahko postane darovalec šele po smrti, pridobitev organov ne sme povzročiti smrti darovalca.</td></tr>
</table>

Povzeto po Madridski resoluciji o darovanju organov in transplantaciji

REGISTER OPREDELJENIH OSEB GLEDE DAROVANJA ORGANOV IN TKIV PO SMRTI

Vsak slovenski državljan ima v času življenja pravico in možnost, da se opredeli glede darovanja organov in tkiv. Odločitev formalno potrdimo z vpisom v nacionalni register opredeljenih oseb, ki je bil vzpostavljen leta 2004. Izjavo o opredelitvi glede darovanja lahko podpišemo osebno na številnih pooblaščenih mestih v več krajih po Sloveniji (natančen seznam je objavljen na *www.slovenija-transplant.si*) ali elektronsko z digitalnim podpisom preko portala eUprava *(https://e-uprava.gov.si/)*. Od junija 2017 je poleg opredelitve ZA darovanje mogoča tudi opredelitev PROTI darovanju.

V letu 2019 smo zbrali skupaj 1.254 opredelitev (1.245 ZA in 9 PROTI), od tega 566 po elektronski poti. Do 31. 12. 2019 je bilo v register vpisanih skupaj 9.869 oseb (9.855 ZA in 14 PROTI).

Število vpisanih v registru opredeljenih oseb glede darovanja organov in tkiv po letih v obdobju od 2004 do 2019

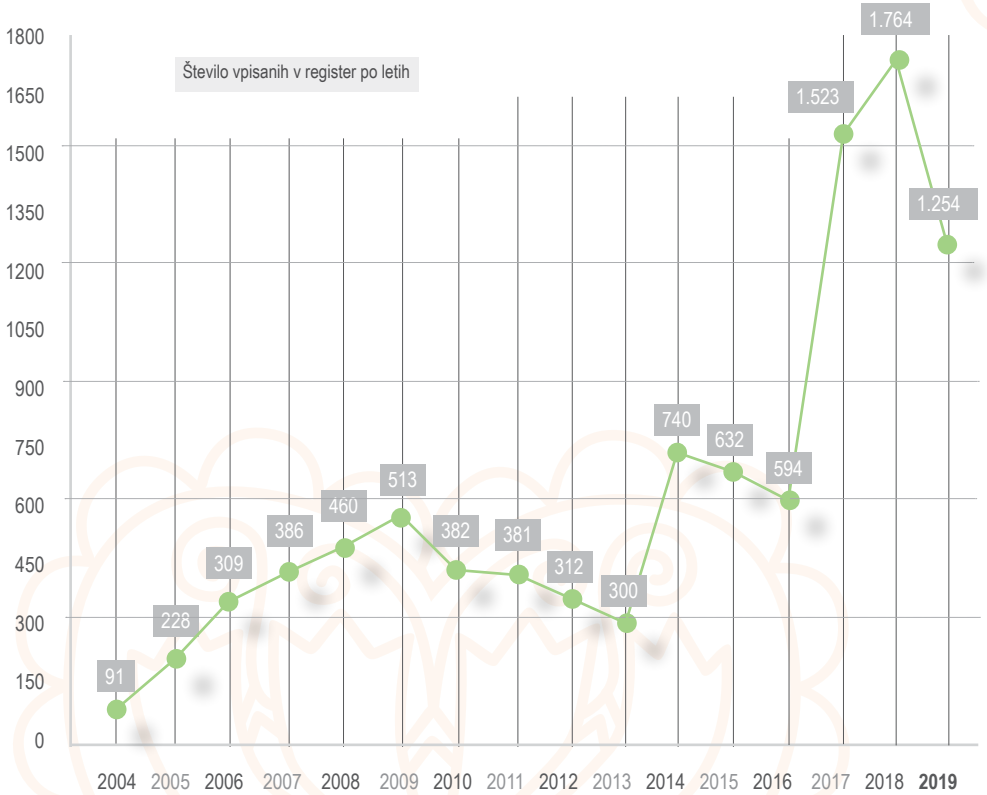
Leto	Št. vpisanih
2004	91
2005	228
2006	309
2007	386
2008	460
2009	513

Leto	Št. vpisanih
2010	382
2011	381
2012	312
2013	300
2014	740
2015	632

Leto	Št. vpisanih
2016	594
2017	1.523
2018	1.764
2019	1.254
SKUPAJ	**9.869**

Vir: arhiv Slovenija-transplanta

Grafični prikaz vpisanih v registru opredeljenih posmrtnih darovalcev po letih v obdobju od 2004 do 2019



ODSTOTKI ODKLONITEV PRI POGOVORU S SVOJCI

Pogovor s svojci oz. bližnjimi osebami možnega mrtvega darovalca (MMD) glede darovanja se opravi v vseh primerih, ko je možno darovanje organov za presaditev. Transplantacijski koordinator šele po potrditvi smrti ter vpisu časa smrti preveri v registru, ali je bil umrli opredeljen kot darovalec po smrti. Kljub znani opredelitvi centralni koordinator za transplantacijo vedno opravi pogovor o darovanju s svojci umrlega. V pogovoru poskuša izvedeti, kakšno je bilo stališče umrlega glede posmrtnega darovanja in v primeru privolitve v nadaljevanju pogovora pridobi dodatne zdravstvene podatke, ki so pomembni za darovanje.

Če volja ni znana, se na koncu odločijo svojci. Vsi postopki so izvedeni z visoko stopnjo tankočutnosti, razumevanja izjemno težkih čustvenih okoliščin ter v skladu z zakonodajnimi določbami in medicinsko doktrino. V letu 2019 se je odstotek odklonitev v primerjavi z letom 2018 občutno zmanjšal, in sicer je darovanje odklonilo 23 % svojcev.

Ker je smrt bližnjega za vsakogar izmed nas težka izkušnja, Slovenija-transplant svojcem darovalcev nudi možnost posvetovanja ob žalovanju s strokovno usposobljeno in izkušeno strokovnjakinjo.

Odstotki odklonitev darovanja v obdobju od 1998 do 2019

Vir: arhiv Slovenija-transplanta

Leto	%
1998	21
1999	30
2000	37
2001	36

Leto	%
2002	22
2003	23
2004	30
2005	19

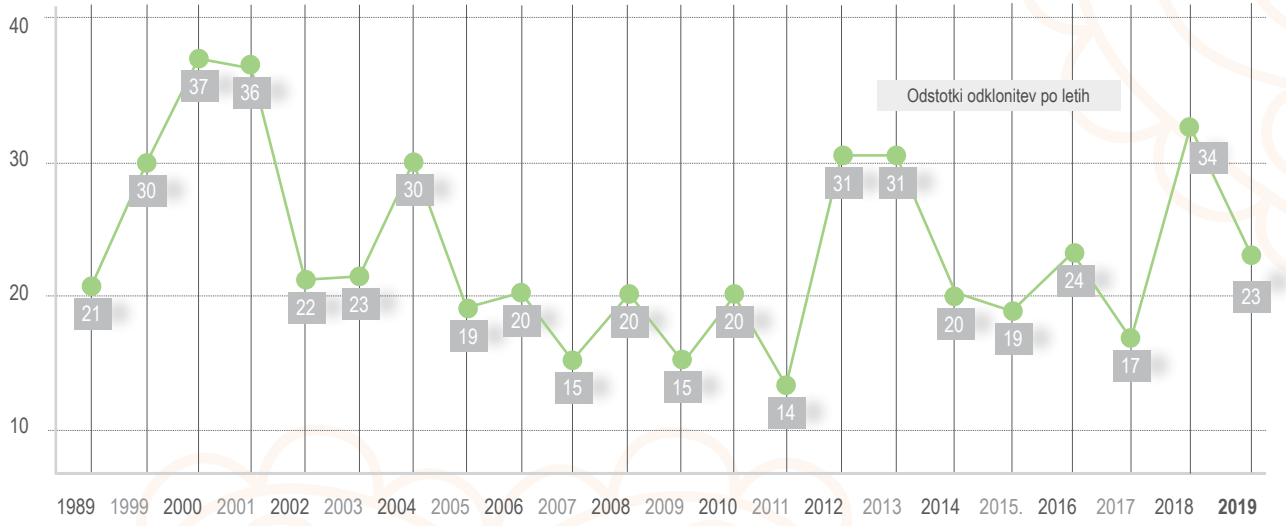
Leto	%
2006	20
2007	15
2008	20
2009	15

Leto	%
2010	20
2011	14
2012	31
2013	31

Leto	%
2014	20
2015	19
2016	24
2017	17

Leto	%
2018	34
2019	23

Grafični prikaz odstotkov odklonitev darovanja v obdobju od 1998 do 2019



DELOVANJE DONORSKIH CENTROV

V slovenski donorski program je vključenih enajst donorskih bolnišnic oz. centrov: UKC Ljubljana in UKC Maribor ter splošne bolnišnice v Celju, Murski Soboti, Novi Gorici, Izoli, na Ptuju, v Novem mestu, Slovenj Gradcu, na Jesenicah in v Brežicah.

V donorskem centru izvajajo naslednje dejavnosti:

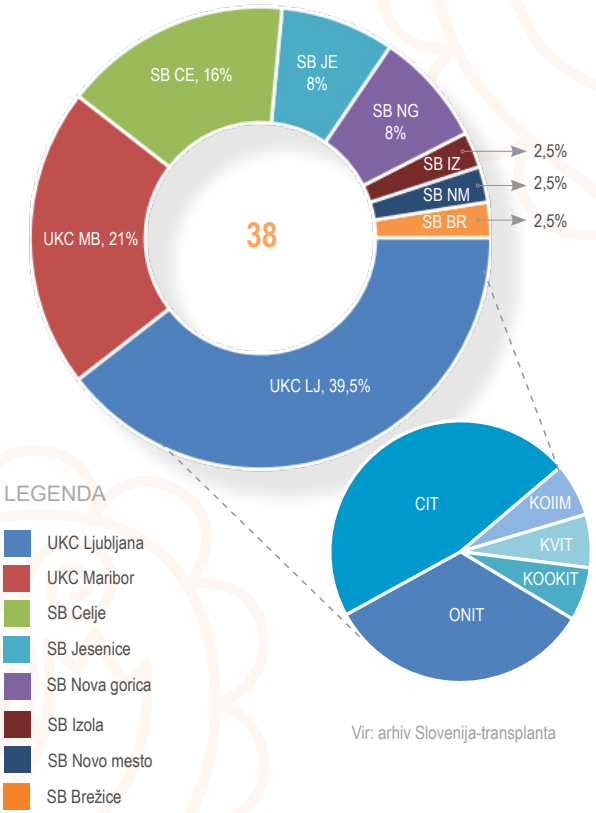
- odkrivajo možne mrtve darovalce,
- izvajajo diagnostiko možganske smrti,
- ugotavljajo primernost organov in tkiv za odvzem in presaditev,
- seznanjajo pokojnikove bližnje z možnostjo darovanja in pridobijo soglasje svojcev,
- ohranjajo delovanje organov mrtvih darovalcev – v intenzivni terapiji in med odvzemom organov,
- sodelujejo pri odvzemih organov in tkiv, ki jih izvajajo slovenske in tuje kirurške ekipe.

Največ darovalcev v Sloveniji pridobijo v UKC Ljubljana, kjer imajo največje število postelj v enotah intenzivne terapije in so v letu 2019 pridobili 15 dejanskih umrlih darovalcev. Rezultati so dobri tudi v UKC Maribor, kjer so v letu 2019 pridobili 8 dejanskih umrlih darovalcev (od 10 aktivnih) in v SB Celje s 6 pridobljenimi dejanskimi umrlimi darovalci (od 7 aktivnih). Od manjših donorskih bolnišnic sta v letu 2019 z odličnimi rezultati izstopali SB Jesenice in SB Nova Gorica s po tremi dejanskimi darovalci, po enega darovalca so pridobili še v SB Izola, SB Novo mesto in v SB Brežice, ki se je donorskemu programu uradno pridružila v letu 2018.

Število in delež dejanskih umrlih darovalcev v posameznih donorskih centrih (DC) v letu 2019

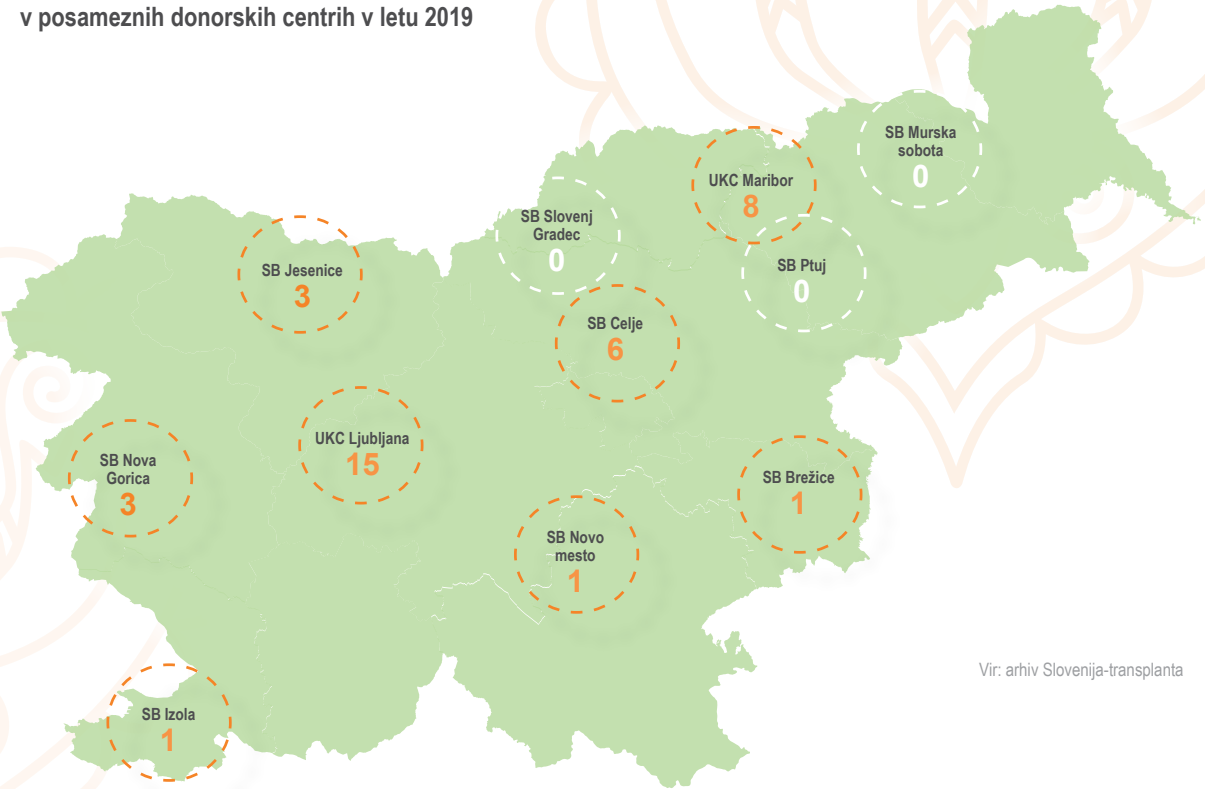
Donorski center	Število MD	Delež v %
UKC Ljubljana skupaj	15	39,5
Od tega ONIT*	5	
Od tega CIT	7	
Od tega KOIIM	1	
Od tega KVIT	1	
Od tega KOKIT	1	
UKC Maribor	8	21
SB Celje	6	16
SB Jesenice	3	8
SB Nova Gorica	3	8
SB Izola	1	2,5
SB Novo mesto	1	2,5
SB Brežice	1	2,5
SKUPAJ	38	100

*ONIT – oddelek nevrološke intenzivne terapije,
CIT – centralna intenzivna terapija,
KOIIM – klinični oddelek interne intenzivne medicine,
KVIT – Kardiovaskularna intenzivna terapija,
KOKIT – Klinični oddelek za otroško kirurgijo in intenzivno terapijo



Vir: arhiv Slovenija-transplanta

Število dejanskih umrlih darovalcev v posameznih donorskih centrih v letu 2019



Vir: arhiv Slovenija-transplanta

OSNOVE DONORSKEGA PROGRAMA
PO **PROGRAMU ETPOD**:
CELODNEVNO IZOBRAŽEVANJE
ZA STROKOVNO ZDRAVSTVENO OSEBJE
V IZVEDBI SLOVENIJA-TRANSPLANTA.

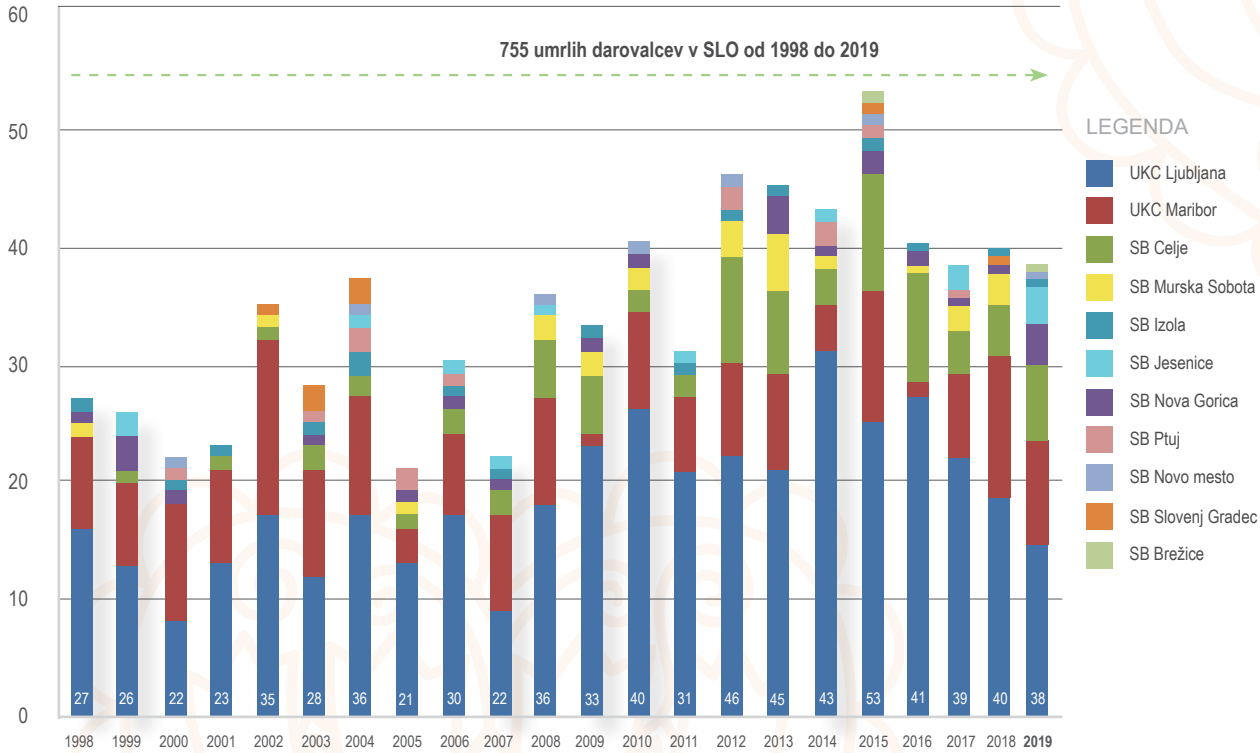
FOTO: Slovenija-transplant

Število dejanskih umrlih darovalcev po donorskih centrih od 1998 do 2019

Vir: arhiv Slovenija-transplanta

Leto	UKC LJ	UKC MB	SB CE	SB MS	SB NG	SB Izola	SB Ptuj	SB JE	SB NM	SB SG	SB Brežice
1998 / 99	16/13	8/7	0/1	1/0	1/3	1/0	0/0	0/2	0/0	0/0	0/0
2000	8	10			1	1	1		1		
2001	13	8	1			1					
2002	17	15	1	1						1	
2003	12	9	2		1	1	1			2	
2004	17	10	2			2	2	1	1	1	
2005	13	3	1	1	1		2				
2006	17	7	2		1	1	1	1			
2007	9	8	2		1	1		1			
2008	18	9	5	2				1	1		
2009	23	1	5	2	1	1					
2010	26	8	2	2	1				1		
2011	21	6	2			1		1			
2012	22	8	9	3		1	2		1		
2013	21	8	7	5	3	1					
2014	31	4	3	1	1		2	1			
2015	25	11	10		2	1	1		1	1	1
2016	28	2	7	1	2	1					
2017	22	7	4	2	1		1	2			
2018	18	13	4	2	1	1				1	
2019	15	8	6		3	1		3	1		1
SKUPAJ	**405**	**170**	**76**	**23**	**24**	**16**	**13**	**13**	**7**	**6**	**2**

Grafični prikaz števila dejanskih umrlih darovalcev po donorskih centrih od 1998 do 2019



Potencial in realizacija v donorskih bolnišnicah (zaključena analiza za leto 2018)

Potencial za darovanje za posamezno donorsko bolnišnico se izraža kot odstotek možgansko umrlih od vseh umrlih na oddelku za intenzivno zdravljenje (OIZ). Pove nam, pri koliko umrlih je bila do konca izpeljana diagnostika možganske smrti. Potencial je v neposredni povezavi z odkrivanjem primernih darovalcev na OIZ.
Realizacija v procesu darovanja nam pove, koliko primernih darovalcev (dokazana možganska smrt) je postalo aktivnih darovalcev. Izraža se kot odstotek aktivnih darovalcev od vseh dokazanih možgansko umrlih na OIZ.

Vir: arhiv Slovenija-transplanta

Donorska bolnišnica	Vse smrti v OIZ	MD	PD	*Potencial (%)	Dosegljivi (%)	AD	Realizacija (%)	**Dosegljiva (%)
UKC Ljubljana	389	83	46	11.8	13.7	18	39	65
UKC Maribor	284	56	25	8.8	13.7	17	68	65
SB Celje	131	39	11	8.4	8.3	7	64	55
SB Murska sobota	70	14	5	7.1	8.3	2	40	55
SB Nova Gorica	90	17	2	2.2	8.3	1	50	55
SB Novo mesto	143	9	4	2.8	8.3	0	0	55
SB Izola	60	9	1	1.6	8.3	1	100	55
SB Jesenice	52	7	2	3.8	8.3	1	50	55
SB Slovenj Gradec	55	8	1	1.8	8.3	1	100	55
SB Ptuj	72	8	0	/	8.3	0	/	55
SB Brežice	47	5	1	2.1	8.3	0	0	55

OIZ – oddelek za intenzivno zdravljenje, **MD** – možni darovalec, **PD** – primerni darovalec (dokazana možganska smrt), **AD** – aktivni darovalec (privolitev svojcev, odvzem organov), **Potencial** - % možgansko umrlih od vseh umrlih na OIZ = % PD/vse smrti na OIZ,
Realizacija - % aktivnih darovalcev od vsem možgansko umrlih = % AD/PD

*Potencial za donorsko bolnišnico je pričakovano višji za bolnišnice, ki imajo svojo nevrokirurško enoto in lahko dosežejo potencial tudi do 13,7 % (dosegljivi potencial). Dokaj blizu svojemu potencialu je bil UKC Ljubljana, medtem ko je UKC Maribor v letu 2018 za svojim potencialom nekoliko zaostal. Za bolnišnice brez lastne nevrokirurške enote je dosegljivi potencial za darovanje do 8,3 %. To številko je leta 2018 celo presegla SB Celje, relativno blizu je bila SB Murska Sobota. Večina donorskih bolnišnic je v letu 2018 še zaostajala za dosegljivimi vrednostmi, kar kaže na to, da lahko še dodatno izboljšamo odkrivanje primernih darovalcev.

Realizacija je odvisna predvsem od odstotka absolutnih medicinskih kontraindikacij in zavrnitev darovanja s strani svojcev v obravnavanem časovnem obdobju.

**Dosegljiva realizacija upošteva do 20 % absolutnih medicinskih kontraindikacij in do 10-odstotno stopnjo odklonitve darovanja s strani svojcev, loči tudi med donorsko bolnišnico z nevrokirurško enoto ali brez nje (razlika 10 %), ostale ovire v donorskem procesu pa skupno predstavljajo do 5 %. Tako je izračunana dosegljiva realizacija za bolnišnice z nevrokirurško enoto 65 %, za tiste brez nevrokirurške enote pa 55 %. V letu 2018 so dosegljivo realizacijo presegli v UKC Maribor, SB Celje, SB Izola in SB Slovenj Gradec. Pri nizkih vrednostih potenciala zasledimo tudi odstopanja, kot npr. v SB Izola in SB Slovenj Gradec, kjer so dosegli 100-odstotno realizacijo pri edinem primeru, pri čimer ni bilo medicinskih kontraindikacij za darovanje, prav tako pa so svojci v darovanje privolili. Pri bolnišnicah, v katerih leta 2018 ni bilo dokazanih možganskih smrti in ni bilo aktivnih darovalcev, sta potencial in realizacija prav tako 0 % oziroma nemerljiva (/).

Seznam odgovornih oseb (t. i. bolnišničnih transplantacijskih koordinatorjev), ki skrbijo za razvoj, potek ter delovanje donorskega programa v posameznih donorskih centrih za leto 2019

Donorski center	Odgovorne osebe
UKC Ljubljana	prim. asist. mag. Rade Stanić, dr. med.
UKC Maribor	Tanja Kuprivec, dr. med.
SB Brežice	Nataša Pirc, dr. med.
SB Celje	Barbara Hudournik, dr. med.
SB Izola	Damjan Polh, dr. med.
SB Jesenice	Andraž Nastran, dr. med.
SB Murska Sobota	prim. Daniel Grabar, dr. med.
SB Nova gorica	Edyta Čerkini, dr. med.
SB Novo mesto	Matej Godnič, dr. med.
SB Ptuj	prim. Majda Šarman, dr. med.
SB Slovenj Gradec	Rok Popič, dr. med.

28. MEDNARODNI SIMPOZIJ INTENZIVNE MEDICINE:
SODELAVCI SLOVENIJA-TRANSPLANTA S KOLEGI IZ HRVAŠKE IN POLJSKE SO PREDSTAVILI NOVOSTI V DONORSKI MEDICINI

FOTO: Slovenija-transplant

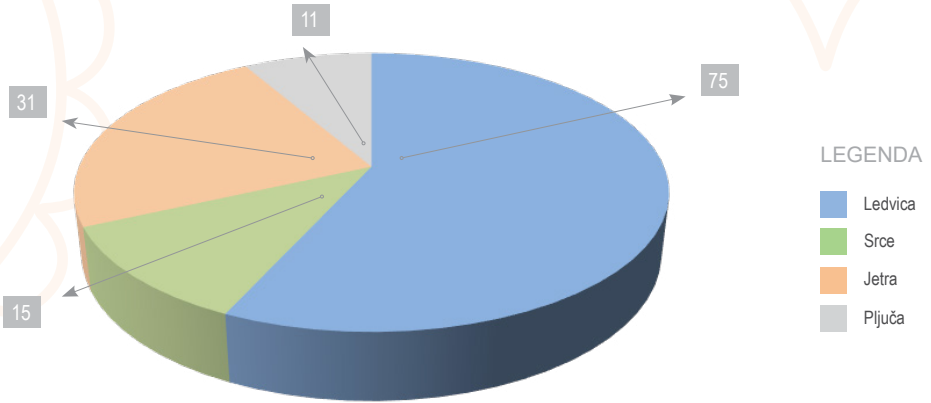
PRIDOBLJENI ČVRSTI ORGANI ZA NAMEN ZDRAVLJENJA

Število pridobljenih organov je odvisno od števila pridobljenih umrlih darovalcev, pa tudi od starosti in medicinskih kontraindikacij. V letu 2019 je bilo število pridobljenih organov umrlih darovalcev iz zgoraj navedenih razlogov nekoliko nižje od preteklih let. V nadaljevanju so prikazani podatki za leto 2019 in primerjava s preteklimi leti.

Število pridobljenih organov slovenskih umrlih darovalcev v letu 2019

Ledvica	Srce	Jetra	Pljuča (obe pljučni krili)	Trebušna slinavka	SKUPAJ
75	15	31	11	0	132

Vir: arhiv Slovenija-transplanta

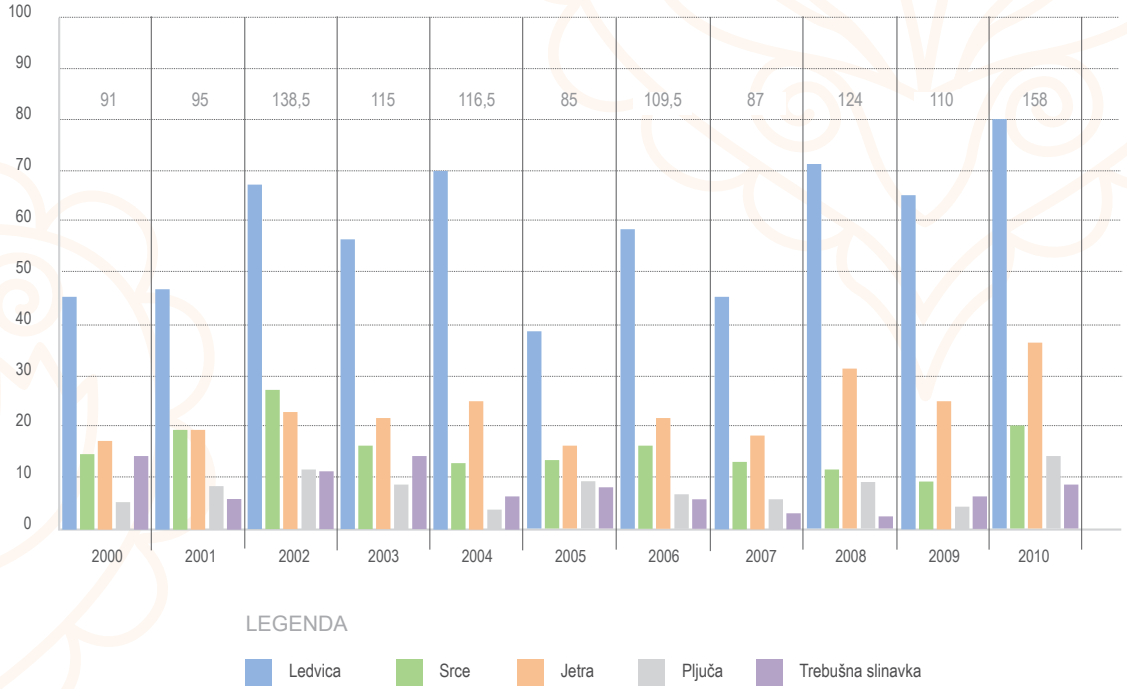


Pridobljeni organi slovenskih umrlih darovalcev od leta 2000 do 2019

Vir: arhiv Slovenija-transplanta

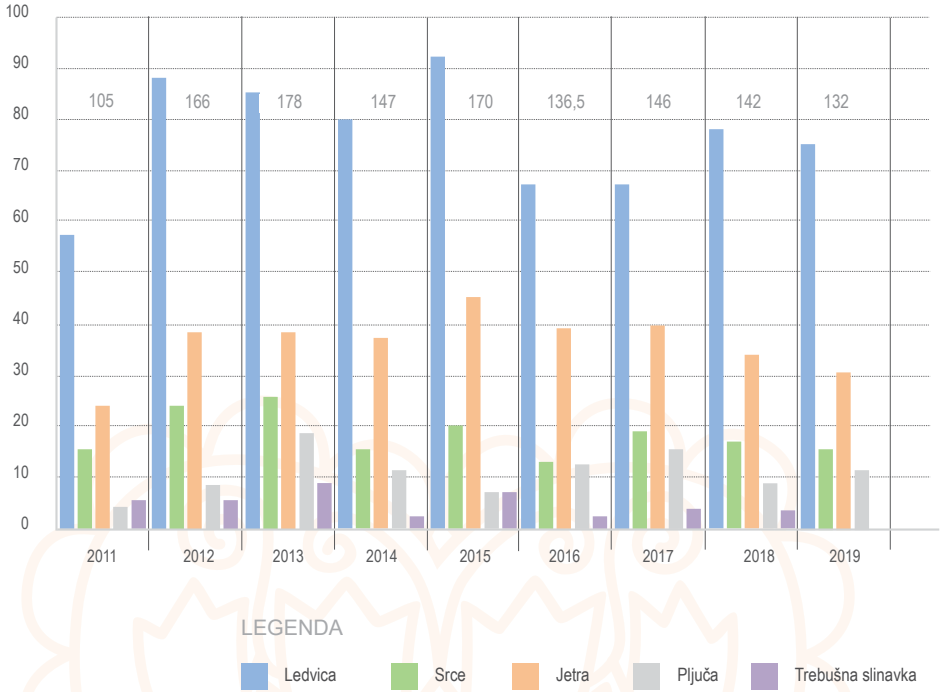
Leto	Ledvica	Srce	Jetra	Pljuča (obe krili)	Trebušna slinavka	SKUPAJ
2000	43	14	17	4	13	91
2001	44	19	19	7	6	95
2002	66	28	22	11,5	11	138,5
2003	56	15	21	8	15	115
2004	70	12	25	3,5	6	116,5
2005	39	13	16	9	8	85
2006	59	16	21	7,5	6	109,5
2007	46	12	19	7	3	87
2008	71	11	31	9	2	124
2009	65	9	26	4	6	110
2010	80	20	37	13	8	158
2011	58	14	24	4	5	105
2012	89	25	39	8	5	166
2013	86	26	39	19	8	178
2014	80	16	38	11	2	147
2015	92	20	46	6	6	170
2016	68	13	39	13,5	2	135,5
2017	68	19	40	15	4	146
2018	79	17	34	9	3	142
2019	75	15	31	11	/	132
SKUPAJ	1.334	334	584	180	119	2.551

Grafični prikaz pridobljenih organov slovenskih umrlih darovalcev od leta 2000 do 2010



Grafični prikaz pridobljenih organov slovenskih umrlih darovalcev od leta 2011 do 2019

2.551 pridobljenih organov umrlih darovalcev v SLO **od 2000 do 2019**



PRESAJENI ČVRSTI ORGANI

V Sloveniji imamo en transplantacijski center, to je Univerzitetni klinični center v Ljubljani, kjer se izvajajo programi za presaditve čvrstih organov. Sistem razporejanja organov zagotavlja enako dostopnost do terapije s presaditvijo organov vsem državljanom Slovenije. Naloge transplantacijskega centra so:

- priprava prejemnikov za uvrstitev na čakalni seznam,
- presaditev organov,
- vodenje bolnikov po presaditvi.

Transplantacijski center od leta 2014 vodi kardiovaskularni kirurg dr. Ivan Kneževič, dr. med.

V letu 2019 je bilo opravljenih 95 presaditev organov. Največ je presajenih ledvic, po številu vseh presajenih organov od umrlih darovalcev na milijon prebivalcev smo nekoliko nad povprečjem držav Eurotransplanta. Pomembno višje pa je število presaditev src na milijon prebivalcev, kjer smo zadnjih nekaj let v samem svetovnem vrhu.

Po obuditvi nacionalnega programa presaditve pljuč v letu 2018 so v UKC Ljubljana v letu 2019 opravili kar deset presaditev obeh pljučnih kril, v enem primeru pa je bila presaditev za slovenskega pediatričnega bolnika opravljena še v AKH na Dunaju, kjer so sicer doslej opravljali presaditve pljuč za slovenske prejemnike.

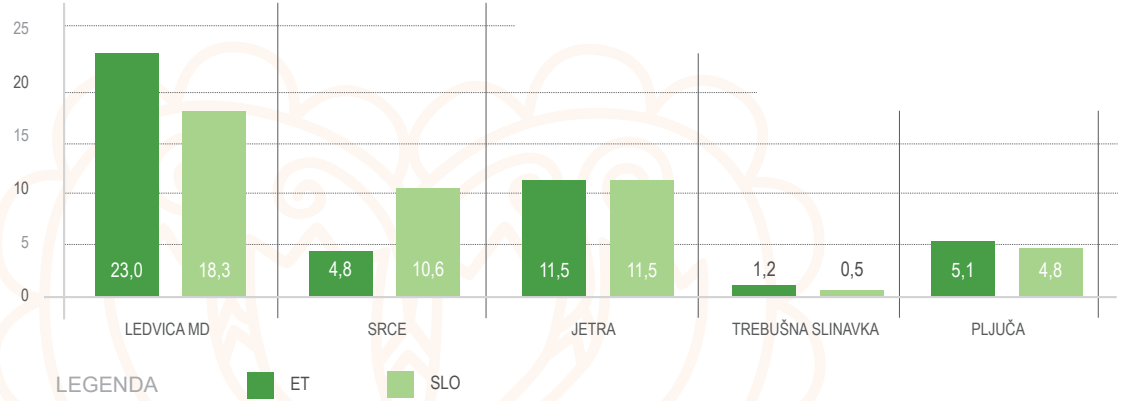
Pediatrične transplantacije delno opravljajo v UKC Ljubljana, delno pa v bližnjih evropskih transplantacijskih centrih (ledvice v LKH v Gradcu, jetra v Bergamu). Za obravnavo in pripravo pred presaditvijo in zdravljenje ter sledenje bolnika po presaditvi organa poskrbijo na pristojnih oddelkih v UKC Ljubljana.

Presajeni čvrsti organi umrlih darovalcev v UKC Ljubljana v letu 2019 in primerjava z Eurotransplantom - absolutno število in število na milijon prebivalcev (NMP)

	Ledvica MD		Srce		Jetra		Trebušna slinavka		Pljuča		SKUPAJ	
	Št.	NMP	Št.	NMP	Št.	NMP	Št.	NMP	Št.	NMP	Št.	NMP
SLO	38	18,3	22	10,6	24	11,5	1	0,5	10	4,8	95	44,7
ET	3.191	23,0	668	4,8	1.571	11,5	156	1,2	1.375	5,1	6.961	44,1

Vir: http://statistics.eurotransplant.org/

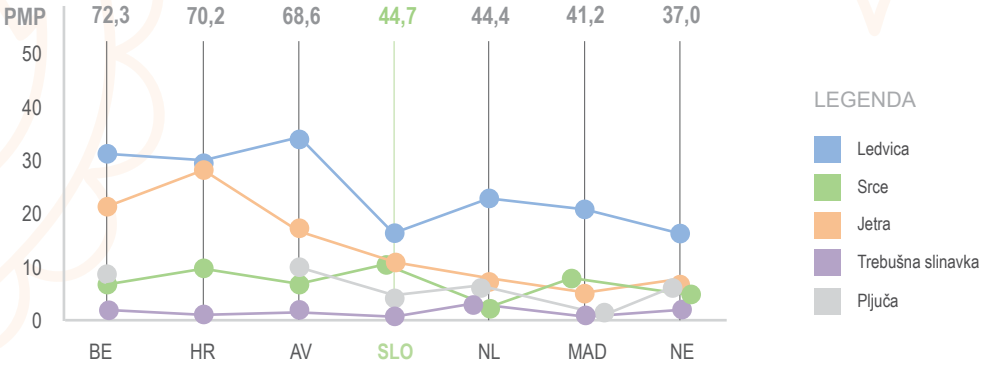
Grafični prikaz presajenih čvrstih organov umrlih darovalcev na miljon prebivalcev (NMP) v UKC Ljubljana v letu 2019 in primerjava z Eurotransplantom



Število presajenih čvrstih organov mrtvih darovalcev na milijon prebivalcev (NMP) v Sloveniji leta 2019 in primerjava z državami Eurotransplanta

Država ET	Ledvica	Jetra	Srce	Trebušna slinavka	Pljuča	Število presaditev/ NMP 2019
1. Belgija (BE)	33,9	22,8	7,3	1,8	9,9	72,3
2. Hrvaška (HR)	31,4	30,2	9,3	1,2		70,2
3. Avstrija (AV)	34,8	15,7	7,6	1,7	11,2	68,6
4. Slovenija (SLO)	18,3	11,5	10,6	0,5	4,8	44,7
5. Nizozemska (NL)	26,0	9,7	2,2	1,7	6,1	44,4
6. Madžarska (MAD)	24,1	8,1	7,4	0,5	1,8	41,2
7. Nemčija (NE)	19,4	9,3	4,1	1,1	4,3	37,0

Vir: http://statistics.eurotransplant.org/



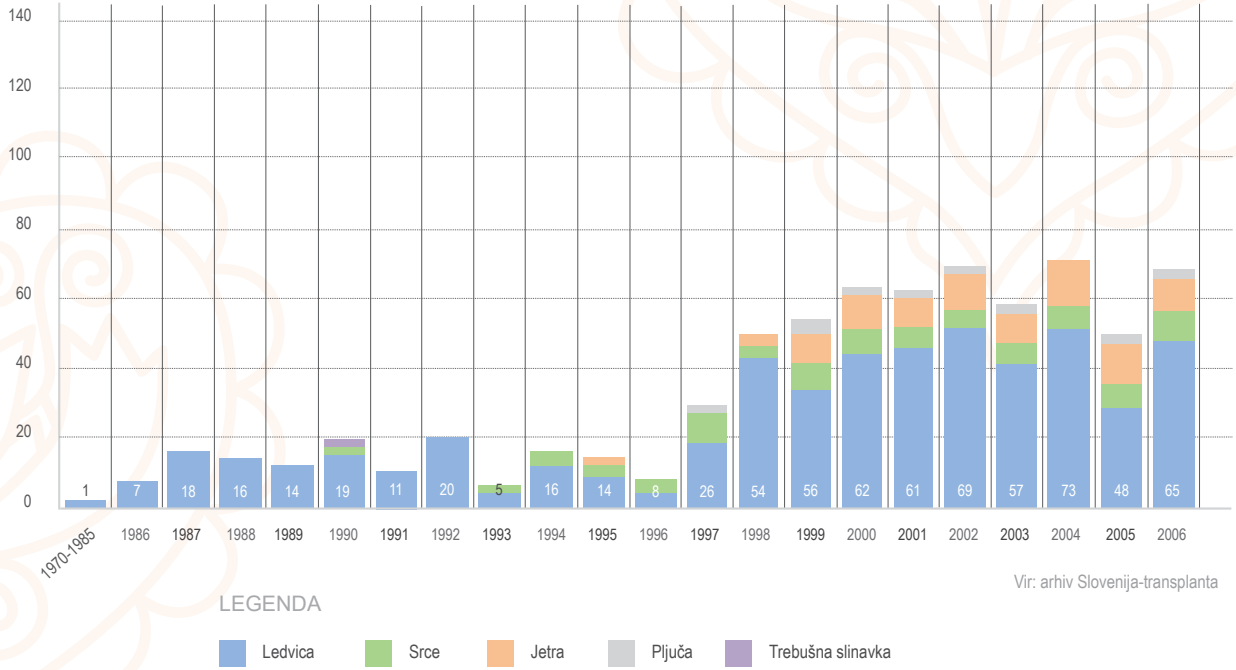
Število presajenih čvrstih organov umrlih darovalcev v Sloveniji od leta 1970 do 2019

Vir: arhiv Slovenija-transplanta

Leto	Ledvica	Srce	Jetra	Pljuča*	Trebušna slinavka	SKUPAJ
Od 1970 do 1985	1					1
1986	7					7
1987	18					18
1988	16					16
1989	14					14
1990	17	1			1	19
1991	11					11
1992	20					20
1993	4	1				5
1994	14	2				16
1995	10	3	1			14
1996	6	2				8
1997	19	6		1		26
1998	46	4	4			54
1999	37	7	9	3		56
2000	44	7	10	1		62
2001	47	4	9	1		61
2002	55	3	11			69
2003	43	3	9	2		57
2004	55	3	15			73
2005	28	5	13	2		48
2006	48	8**	8	2		66
2007	30	11	10	1		52
2008	52	6	22	4		84
2009	43	18	18	2	2	83
2010	61	19	23	3	1	107
2011	46	14	20	7	1	88
2012	62	29***	27	2		120
2013	60	30	21	8	4	123
2014	55	33	31	3		122
2015	64	24	24	7	5	124
2016	44****	31	27	10	5	117
2017	46****	24	23	8		101
2018	54****	23	27	7	3	114
2019	38	22	24	11	1	96
SKUPAJ	1.215	343	386	85	23	2.052

*Večina presaditev pljuč pri slovenskih prejemnikih je bila do vključno leta 2018 opravljena v AKH na Dunaju, z izjemo 2003 (1 presaditev v UKC LJ) in 2018 (2 presaditvi v UKC LJ). V letu 2019 je bilo v UKC Ljubljana opravljenih 10 presaditev pljuč in ena pediatrična presaditev v AKH Dunaj.
** Eno srce slovenskega darovalca je bilo presajeno slovenskemu bolniku v Gradcu.
*** Eno srce je bilo skupaj s pljuči presajeno slovenskemu bolniku na Dunaju.
**** V letih 2016, 2017 in 2018 sta bili opravljeni tudi po dve presaditvi ledvice živega sorodnega darovalca.
Skupno število presajenih ledvic v letu 2016 je torej 46, v letu 2017 48 in v letu 2018 56 ledvic.

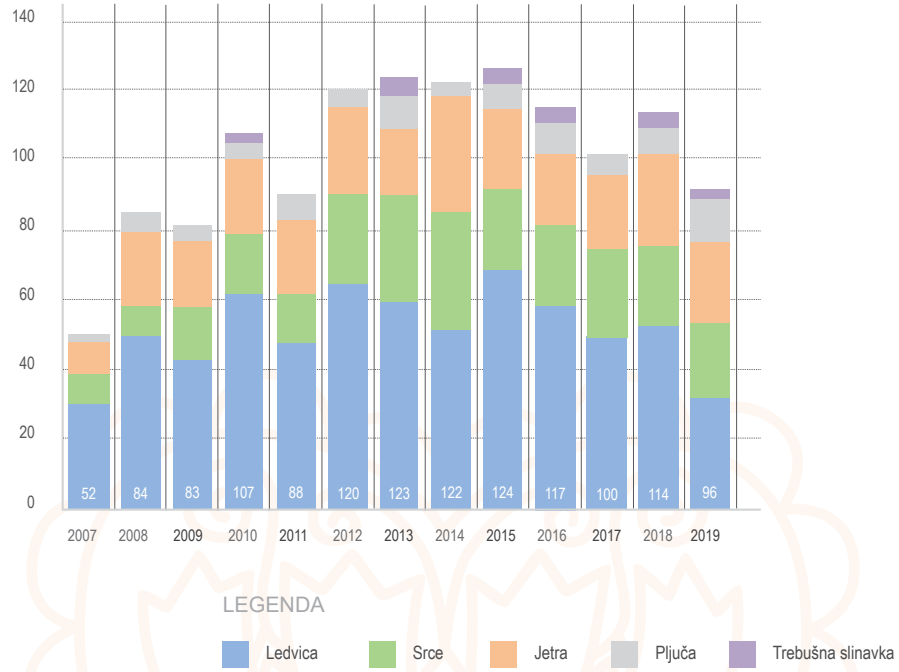
Grafični prikaz števila presajenih čvrstih organov umrlih darovalcev v Sloveniji od leta 1970 do 2006



Vir: arhiv Slovenija-transplanta

Grafični prikaz števila presajenih čvrstih organov umrlih darovalcev v Sloveniji od leta 2007 do 2019

2.052 presajenih čvrstih organov umrlih darovalcev v SLO **od 1970 do 2019**



Vir: arhiv Slovenija-transplanta

USPEŠNOST SLOVENSKIH PROGRAMOV ZA PRESADITVE ORGANOV

Preživetje bolnikov po presaditvi srca

Od leta 1990 do konca 2019 je bilo v UKC Ljubljana opravljenih 343 presaditev srca, v letu 2019 so presadili 22 src. 18 (82 %) bolnikov je bilo transplantiranih urgentno, 4 (18 %) pa redno. Glede na podatke Eurotransplanta se je UKC Ljubljana ponovno uvrstil med prvih 10 (od 42) največjih centrov za presaditve srca v območju Eurotransplanta in se po številu opravljenih presaditev lahko primerja z največjimi centri Nemčije, Belgije, Madžarske in Avstrije.

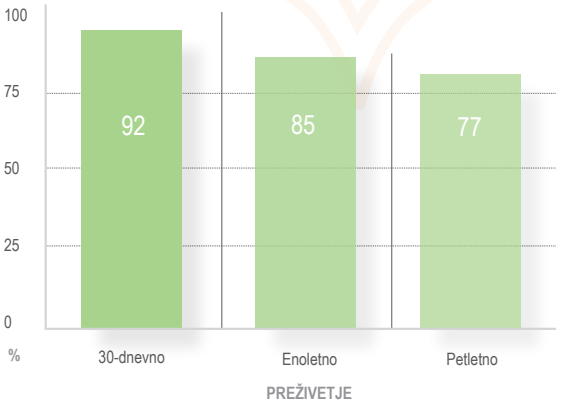
Večletno povprečje (2009-2018) čakalne dobe za elektivno presaditev srca znaša približno 248 dni (mediana 67 dni), za urgentno presaditev srca pa približno 50 dni (mediana 50 dni). V letu 2019 je bila povprečna čakalna doba za elektivno presaditev srca 452 dni (mediana 238 dni) in za urgentno presaditev 59 dni (mediana 50 dni).

Rezultati preživetja bolnikov po presaditvi so primerljivi z rezultati iz mednarodnega referenčnega registra ISHLT *(The International Society for Heart & Lung Transplantation)*.

Preživetje odraslih bolnikov po presaditvi srca v % (za obdobje 1990–2018, n=321)

30-dnevno preživetje	Enoletno preživetje	Petletno preživetje
92 %	85 %	77 %

Vir: Poročilo o delovanju programa za napredovalo srčno popuščanje in presaditev srca za leto 2019 (KO za kardiologijo, UKC Ljubljana)

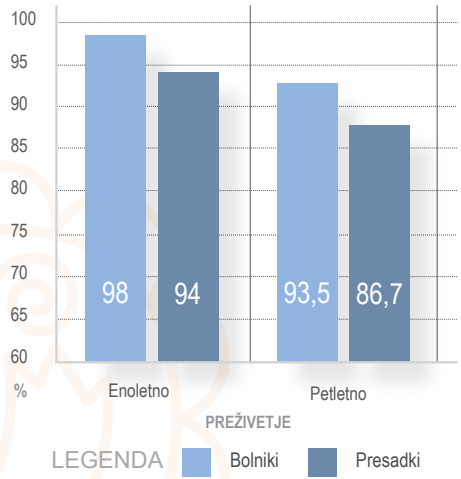


Preživetje bolnikov po presaditvi ledvice

V Sloveniji je bilo v obdobju po priključitvi Eurotransplantu (1. 1. 2000–31. 12. 2019) presajenih 983 ledvic živih in umrlih darovalcev. V prvem letu po presaditvi so pri 12,7 % vseh bolnikov s presajenim organom zaznali klinično, z biopsijo dokazano akutno zavrnitev presadka. Pojavnost klinične, z biopsijo dokazane zavrnitve presajene ledvice je primerljiva s podatki v literaturi in z drugimi centri v razvitem svetu.
Nekaterim prejemnikom so ledvico presadili v kombinaciji z drugimi organi (trebušna slinavka, jetra, srce).
Mediani čas od uvrstitve na čakalno listo do presaditve je približno 300 dni za obdobje od 2013 do 2016. Po podatkih Eurotransplanta za triletno obdobje (2010–2014) v prvem letu po vključitvi na čakalni seznam presadimo ledvico 55 % bolnikom, po treh letih pa približno 80 % bolnikom.
Aktualno 1- in 5-letno preživetje slovenskih bolnikov in presadkov je po podatkih Eurotransplanta za obdobje 2000–2014 nad povprečjem držav članic Eurotransplanta in je primerljivo z najrazvitejšimi centri v svetu.

Preživetje bolnikov in presadkov po presaditvi ledvice v % (za obdobje 2000–2019, n=983)

Enoletno preživetje	Petletno preživetje
Bolniki	
98 %	93,5 %
Presadki	
94%	86,7 %



Vir: Kazalniki kakovosti Centra za transplantacijo ledvic (KO za nefrologijo, UKC Ljubljana)

Preživetje bolnikov po presaditvi jeter

V obdobju od 1995 do 31. 12. 2019 je bilo v UKC Ljubljana opravljenih 386 presaditev jeter. 63 % bolnikov je potrebovalo presaditev zaradi ciroze jeter, 10 % zaradi akutne odpovedi jeter, 9,7 % zaradi raka na jetrih, 9,3 % zaradi holestatske/kongenitalne bolezni in 2,1 % zaradi presnovne bolezni jeter. Med ostale vzroke za presaditev (5,9 %) sodijo še benigni jetrni tumorji ali policistična bolezen jeter in Budd-Chiarijev sindrom.

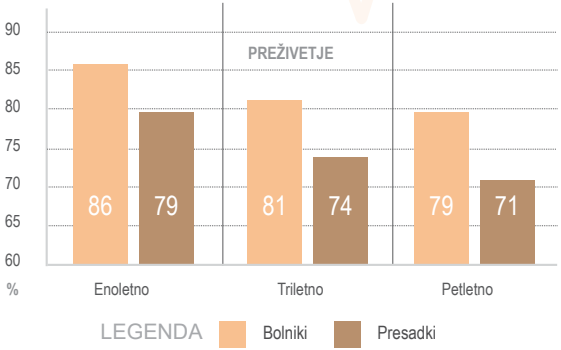
Povprečna čakalna doba za presaditev jeter za leto 2019 je približno 254 dni, mediana znaša 115 dni.

Preživetje bolnikov in presadkov po presaditvi jeter v % (za obdobje 1988–junij 2018*, n=291 (bolniki) in n= 323 (presadki)

Enoletno preživetje	Triletno preživetje	Petletno preživetje
Bolniki		
86 %	81 %	79 %
Presadki		
79 %	74 %	71 %

Vir:ELTR (European Liver Transplant Registry, SLLUBL: Specific Analyses, december 2018)

* Podatki za leto 2019 bodo na voljo šele v sredini leta 2020, zato objavljamo podatke za leto 2018



Vir: Podatki KO za gastroenterologijo UKC Ljubljana

Preživetje bolnikov po presaditvi trebušne slinavke (sočasno z ledvico)

V obdobju od februarja 2009 do 31. 12. 2019 je bilo v Sloveniji opravljenih 22 sočasnih presaditev ledvice in trebušne slinavke. V letu 2019 je bila opravljena 1 sočasna presaditev ledvice in trebušne slinavke.

Po 1 letu je bilo delujočih 17 trebušnih slinavk, 5 trebušnih slinavk je bilo odstranjenih v zgodnjem potransplantacijskem obdobju.

Enoletno preživetje trebušnih slinavk znaša 77,8 % (n = 18), triletno preživetje prav tako 77,8 % (n = 18). Enoletno preživetje ledvic pri bolnikih po sočasni presaditvi ledvice in trebušne slinavke znaša 94,4 %, triletno preživetje prav tako 94,4 %.

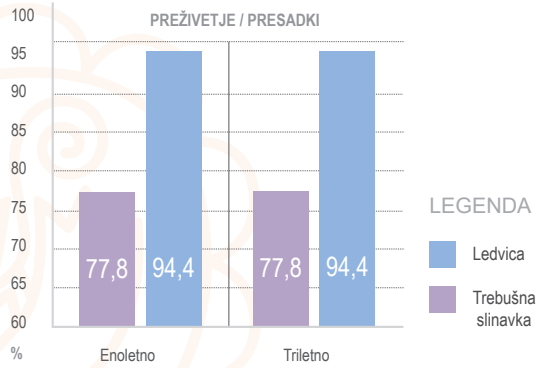
Enoletno, triletno in petletno preživetje bolnikov s presajeno ledvico in trebušno slinavko je bilo 100-odstotno.

Vsi bolniki (n = 21), ki so imeli po enem letu delujočo trebušno slinavko, so bili na dan 31. 12. 2019 inzulinsko neodvisni. En bolnik je umrl 6 let po presaditvi z delujočo trebušno slinavko in ledvico.

Preživetje bolnikov in presadkov po sočasni presaditvi trebušne slinavke in ledvice v % (za obdobje 1988–2019, n = 22 (bolniki) in n = 18 (presadki))

Enoletno preživetje		Triletno preživetje	
Bolniki			
100 %		100 %	
Presadki			
T. slinavka	Ledvica	T. slinavka	Ledvica
77,8 %	94,4 %	77,8 %	94,4 %

Vir: Poročilo – izr. prof. dr. Damjan Kovač, dr. med. (KO za nefrologijo, UKC Ljubljana)



Preživetje bolnikov po presaditvi pljuč v % (za obdobje 1997–2019, n = 85)

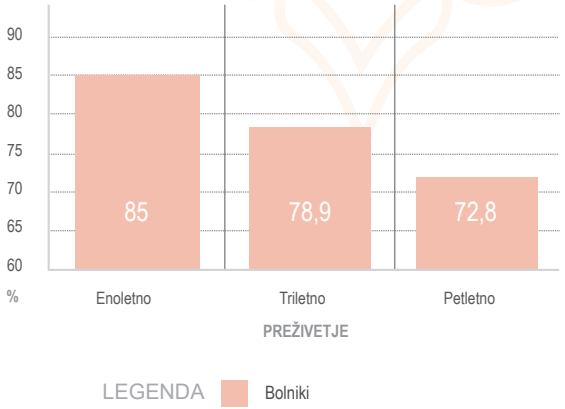
V obdobju 1997–2019 je bilo pri slovenskih bolnikih opravljenih 85 presaditev pljuč, od tega je bila pri enem bolniku opravljena ponovna presaditev. V letu 2018 so v UKC Ljubljana ponovno pričeli z lastnim programom presaditve pljuč in v letu 2019 opravili 10 transplantacij obeh pljučnih kril. Prva transplantacija enega pljučnega krila je bila v UKC Ljubljana opravljena leta 2003.

V letu 2019 je bilo pri slovenskih bolnikih skupaj opravljenih 11 presaditev pljuč, od tega 1 pediatrična presaditev v univerzitetni bolnišnici (AKH) na Dunaju.

Preživetje bolnikov po presaditvi pljuč v % (za obdobje 1997–2019, n=85)

Enoletno preživetje	Triletno preživetje	Petletno preživetje
Bolniki		
85 %	78,9 %	72,8 %

Vir: Poročilo - doc. dr. Matevž Harlander, dr. med.
(KO za pljučne bolezni in alergologijo, UKC Ljubljana)



Tkiva in celice

PRESADITVE KRVOTVORNIH MATIČNIH CELIC

Presaditev krvotvornih matičnih celic (KMC) je najbolj razširjena oblika celičnega zdravljenja, saj se na ta način zdravi več kot 70 malignih in nemalignih bolezni, pri določenih hematoloških obolenjih pa je glavna terapevtska in tudi edina možnost za ozdravitev. Sodoben način zdravljenja s KMC v optimalnih pogojih dosega več kot 90-odstotno uspešnost *(http://www.ztm.si)*. Za takšen uspeh pa je potrebno dobro imunsko (HLA) ujemanje darovalca in prejemnika. Sistem HLA je pri vsakem človeku zelo raznolik in zato je najti ustrezen par zahtevno delo. V mednarodni skupnosti so se zdravniki odločili za ustanovitev večjih registrov tipiziranih prostovoljnih darovalcev KMC, ki bi omogočali bistveno večjo možnost za ujemanje HLA in s tem uspešnost presaditve.

Poznamo več vrst ujemanja med darovalcem in prejemnikom. Kadar je možno uporabiti lastne KMC, to imenujemo avtologno darovanje. Če to ni možno, iščemo drugega darovalca, ki je s prejemnikom v sorodu ali pa ne. Darovanje drugega darovalca imenujemo tudi alogenično, pri čemer iščemo darovalca v Sloveniji in nato v tujini.

Register Slovenija-donor

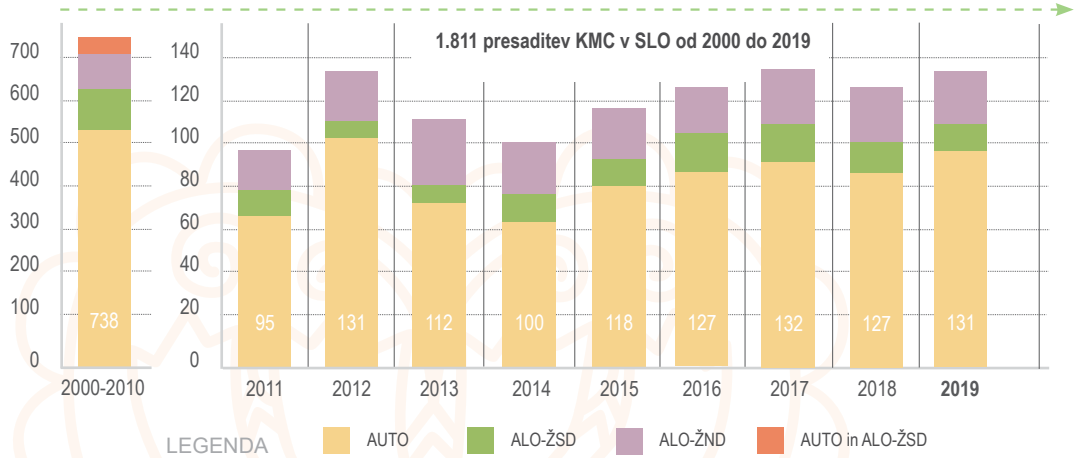
V Sloveniji je bil leta 1991 ustanovljen register nesorodnih darovalcev Slovenija Donor, ki je naslednje leto postal polnopravni član svetovnega registra *Bone Marrow Donors Worldwide (BMDW)*. Na dan 31. 12. 2019 je bilo v register Slovenija Donor vpisanih 20.597 oseb, od tega jih je bilo v svetovni register BMDW vpisanih 19.475.

Presaditve KMC v Sloveniji od leta 2000 do 2019

Tip presaditve	2000-2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
AUTO	531	68	101	74	63	84	86	92	88	89
ALO-ŽSD	102	9	8	7	11	10	15	12	13	11
ALO-ŽND	84	18	22	31	26	24	26	28	26	31
AUTO in ALO-ŽSD	21									
SKUPAJ	738	95	131	112	100	118	127	132	127	131

AUTO – avtologne presaditve, **ALO** – alogenske presaditve, **ŽSD** – živi sorodni darovalec, **ŽND** – živi nesorodni darovalec

Vir: Letno poročilo ZTM – Slovenija donor, podatke mesečno zbiramo za arhiv Slovenija-transplanta.



PROGRAM PRIDOBIVANJA IN PRESADITVE ROŽENIC

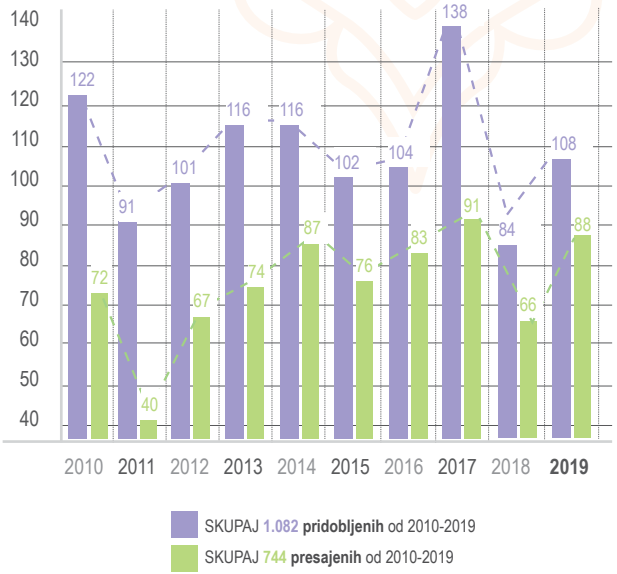
Zdravljenje s presaditvijo roženic je ena najpogostejših in tudi najuspešnejših presaditev tkiv na svetu. Takšen način zdravljenja pogosto predstavlja edini način, s katerim izboljšamo vid zaradi predhodnega obolenja oz. poškodb. V Sloveniji pridobivamo roženice od umrlih darovalcev po dokončni zaustavitvi srca ali po dokazani možganski smrti.

Pridobljene in presajene roženice od leta 2010 do 2019

Leto	Št. pridobljenih roženic	*Št. presajenih roženic
2010	122	72
2011	91	40
2012	101	67
2013	116	74
2014	116	87
2015	102	76
2016	104	83
2017	138	91
2018	84	66
2019	108	88

* Podatki o presaditvah na Očesni kliniki UKC Ljubljana v obdobju 2010–2017, od leta 2018 dalje pa so vključene tudi presaditve na Oddelku za očesne bolezni UKC Maribor

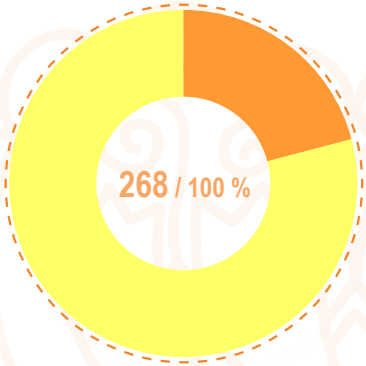
Vir: arhiv Slovenija-transplant



Odvzem roženic je možen po predhodni privolitvi umrle osebe v času življenja oz. ob nenasprotovanju bližnjih. Dokončno odločitev o primernosti roženice za presaditev vselej sprejme prejemnikov odgovorni zdravnik. Presaditev roženice izvajamo v dveh transplantacijskih centrih: na Očesni kliniki v UKC Ljubljana ter na Oddelku za očesne bolezni v UKC Maribor.

Čakalni seznam bolnikov za presaditev roženice na Očesni kliniki v UKC Ljubljana (na dan 1. 4. 2020)

Diagnoza	Število bolnikov
Keratokonus	56
Ostale diagnoze	212
SKUPAJ	**268**



LEGENDA

- Keratokonus: **56 bolnikov (21 %)**
- Ostale diagnoze: **212 bolnikov (79 %)** (poškodbe, degeneracija, retransplantacija, makule roženice, distrofija Fuchs, endotelna distrofija, cornea guttata, afaka in psevdofaka, keratopatija bullosa, vnetja, drugo)

Vir: Očesna klinika Ljubljana

OSTALA TKIVA IN CELICE

Sledljivost in transparentnost v programih presaditve oz. uporabe tkiv in celic za namen zdravljenja

V Slovenija-transplantu smo vzpostavili sodelovanje z vsemi ustanovami za tkiva in celice, ki morajo imeti veljavno dovoljenje Javne agencije za zdravila in medicinske pripomočke (v nadaljevanju: JAZMP). Sledljivost in transparentnost zagotavljamo z zbiranjem in pregledovanjem sprotnih poročil ustanov za tkiva in celice, ki nam poročajo o darovanju, pridobivanju, procesiranju, shranjevanju, dodeljevanju, uporabi in uničenju tkiv in celic.

Po zaključku leta na osnovi letnih poročil posameznih ustanov za tkiva in celice v Slovenija-transplantu pripravimo zbirno letno poročilo. Prav tako pripravimo letno zaključno poročilo o hudih neželenih dogodkih in reakcijah ter ga posredujemo JAZMP, ki nato poroča Evropski komisiji.

Ustanove za tkiva in celice ter zagotavljanje kakovosti in varnosti

V Sloveniji je na nacionalni ravni v dejavnost preskrbe s tkivi in celicami vključenih 26 ustanov. Od tega je v program vključenih 15 bolnišnic in znotraj teh 40 kliničnih oddelkov. Glede na status je 18 ustanov za tkiva in celice javnih in 8 ustanov zasebnih. Zasebne ustanove imajo dovoljenje izključno za avtologno pridobivanje tkiv in celic.

Slovenija-transplant in JAZMP zagotavljata delovanje sistema ter sproti ugotavljata in obravnavata vse odklone, ki lahko vplivajo na kakovost in varnost tkiv in celic darovalcev, prejemnikov in osebja, ki je vključeno v posamezne procese.

Za pridobitev dovoljenja mora vsaka ustanova izpolnjevati stroge strokovne in zakonske pogoje. Vse ustanove imajo vzpostavljen sistem kakovosti, v katerem so opisani vsi postopki za zagotavljanje pogojev za kakovost tkiv in celic ter varnost prejemnikov. Vse ustanove redno nadzoruje JAZMP, v preverjanje sporočenih podatkov pa je vključen tudi Slovenija-transplant.

Oploditev z biomedicinsko pomočjo in reproduktivne celice

V Sloveniji so registrirani 4 centri za dejavnost oploditve z biomedicinsko pomočjo parom, ki ne morejo zanositi po naravni poti: OBMP Ljubljana, OBMP Maribor, OBMP Postojna in ZC Dravlje. Obseg dejavnosti je razviden iz tabele o pridobljenih in uporabljenih tkivih in celicah. Omenjeno področje spada po številu izvedenih postopkov med najobsežnejše.

V letu 2019 je Ministrstvo za zdravje RS vzpostavilo strokovno skupino, v kateri sodelujejo centri za OBMP Ljubljana, Maribor, Postojna, zasebni zavod Zdravje in zavod Slovenija-transplant. Skupina pripravlja strokovne smernice in zakonodajo za vzpostavitev nacionalnega registra OBMP, v katerega bodo posamezni centri OBMP v predvidenem časovnem roku sporočali podatke o svoji dejavnosti. Upravitelj registra bo NIJZ, kjer bo ta register tudi fizično nameščen. Zavod Slovenija-transplant bo imel dostop do podatkov za namen zagotavljanja sledljivosti, transparentnosti ter kakovosti in varnosti tkiv in celic.

Pridobivanje in shranjevanje popkovnične krvi in popkovnice

V Sloveniji pridobivamo tudi krvotvorne matične celice iz popkovnične krvi in popkovnice ter tudi drugih tkiv (npr. mlečni zobje). Dovoljenje za delo imajo ena javna tkivna banka – Zavod za transfuzijsko medicino (v nadaljevanju: ZTM) in tri zasebne ustanove (Izvorna celica, Biobanka in FH-S). Javna banka popkovnične krvi pri ZTM je s 1. 12. 2014 zaključila s sprejemanjem vzorcev popkovnične krvi, saj je bilo zbranih in shranjenih zadostno število vzorcev, da lahko zadostijo potrebam v Sloveniji.

Število pridobljenih tkiv in celic od 2009 do 2019

Leto	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Koža*	28	45	22	36	85	89	52	57	32	22	24
Kosti*	38	123	108	67	93	82	147	74	80	78	71
Mehkokostni presadki*	22	39	/	3	11	3	9	/	12	/	/
Hrustanec*	37	21	4	12	11	11	12	/	/	/	/
Reproduktivne celice (št. celic)	15.854	43.472	8.640	27.479	41.929	37.542	39.769	26.191	36.338	13.778	26.813

*Enota: število odvzetih vzorcev

Število uporabljenih tkiv in celic od 2009 do 2019

Leto	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Koža*	36	10	14	34	67	23	31	28	/	20	3
Kosti*	23	47	57	97	59	62	92	82	72	71	81
Mehkokostni presadki*	12	/	2	2	3	4	3	5	2	3	5
Hrustanec*	15	/	3	7	4	9	5	1	/	/	1
Reproduktivne celice*	1.450	2.018	29.651	23.330	23.506	27.271	31.127	26.620	31.817	12.110	5.109

*Enota: število uporabljenih vzorcev

Vir: arhiv Slovenija-transplanta

Število enot pridobljene popkovnične krvi

Ustanova / Leto	2015	2016	2017	2018	2019
Izvorna celica	76	144	107	82	81
Biobanka	175	178	266	110	224
FH-S	8	45	101	169	192
Neocelica	238	0*	0*	0*	0*

*Ustanova prenehala z delovanjem

Število enot pridobljene popkovnice

Ustanova / Leto	2015	2016	2017	2018	2019
Izvorna celica	60	116	96	52	73
Biobanka	32	150	222	96	212
FH-S	8	42	96	114	196
Neocelica	198	0*	0*	0*	0*

*Ustanova prenehala z delovanjem

Vir: arhiv Slovenija-transplanta

NEŽELENI DOGODKI IN REAKCIJE

Slovenija-transplant je odgovoren za obravnavo neželenih dogodkov in reakcij ter odklonov na področju preskrbe s tkivi in celicami zaradi presaditve, t. i. histovigilanco. Namen zbiranja poročil o neželenih dogodkih in reakcijah ali tudi postavitev suma nanje je zagotavljanje kakovosti postopkov in s tem preprečevanja škode ali celo izgube tkiv in celic.

Poročanje poteka na predpisanih obrazcih, za posamezen primer je treba oddati začetno in končno poročilo. Oba obrazca sta prilogi Pravilnika o histovigilanci. Poročanje poteka v več fazah: zaznava odklona, natančen opis, sprejem ustreznih ukrepov za preprečitev škode na tkivih in celicah ter ljudeh, poročanje ustreznim inštitucijam in obveščanje vseh ustanov za tkiva in celice, ki so dobila tkiva in celice, pri katerih je prišlo do odklona.

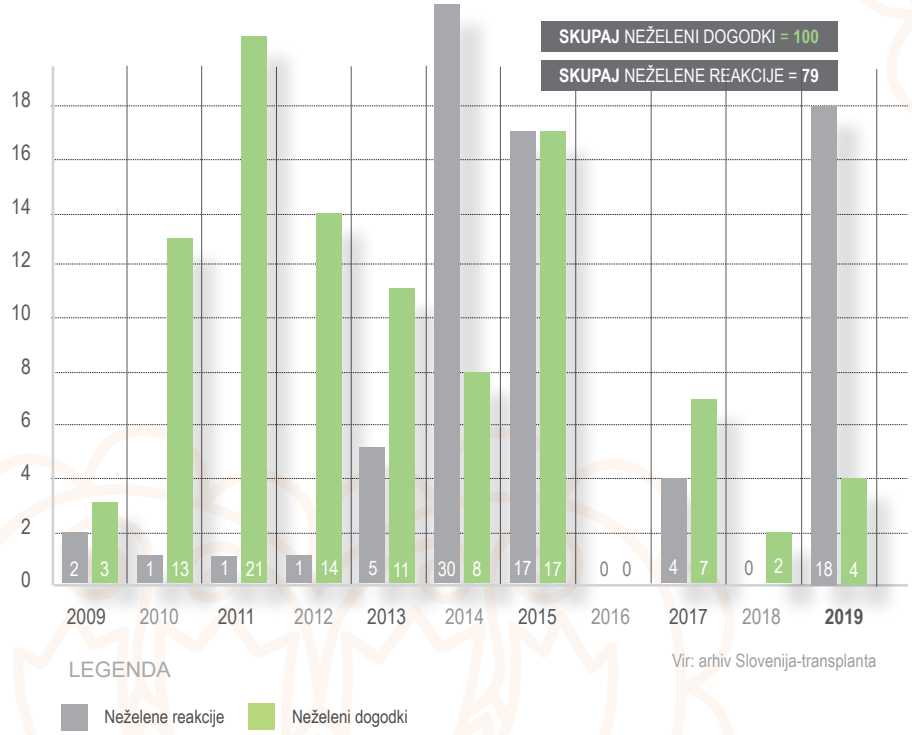
Vsi podatki, ki se zbirajo v sistemu histovigilance, so anonimizirani, da se zagotovi zasebnost in na drugi strani upošteva t. i. kultura neobtoževanja, kar pomeni, da se spodbuja poročanje, iščejo se rešitve oz. izboljšave in ni obsojanja izvajalcev na osebni ravni.

V letu 2019 je Slovenija-transplant prejel 4 poročila o neželenih dogodkih, ki so nastala v verigi preskrbe s tkivi in celicami. Dva primera sta bila zaznana v centru OBMP in dva pri pridobivanju kosti. Pripravili smo analizo in korektivne ukrepe. V vseh štirih primerih ni bilo težjih posledic, tveganje za ponovitev je bilo ocenjeno kot nizko.

V centru OBMP smo obravnavali tudi 18 primerov neželenih reakcij. V šestih primerih je šlo za sindrom ovarijske hiperstimulacije, kjer je bilo 6 pacientk sprejetih na bolnišnično zdravljenje. V 12 primerih pa je prišlo do močnejše venozne krvavitve, a hospitalizacija ni bila potrebna.

Ugotavljamo, da je treba zaradi boljše ozaveščenosti organizirati dodatno izobraževanje na temo histovigilance in poročanja o neželenih dogodkih, saj je možno, da je sporočanje podatkov glede vigilančnih primerov nekoliko podcenjeno.

Grafični prikaz števila neželenih dogodkov in reakcij od 2009 do 2019



Vir: arhiv Slovenija-transplanta

OBJAVE IN PREDAVANJA NA KONFERENCAH

Pregledni in izvirni znanstveni članki

- Berzelak, N., Avsec, D., Kamin, T. (2019). Reluctance and willingness for organ donation after death among the Slovene general population / Zadržki in pripravljenost darovati organe po smrti med splošno javnostjo v Sloveniji. Zdravstveno varstvo / Slovenian journal of public health, 58(4): 155–163.
  Dostopno na: https://content.sciendo.com/view/journals/sjph/58/4/article-p155.xml.
- Lušicky, P., Avsec, D. (2019). Vloga zavoda Republike Slovenije za presaditve organov in tkiv Slovenija-transplant v donorskem programu. Zdravniški vestnik, 88(1–2): 3–20.
  Dostopno na: https://vestnik.szd.si/index.php/ZdravVest/article/view/2833.
- Avsec, D. (2019). Darovanje in pridobivanje delov človeškega telesa za namen zdravljenja. V Kremžar, B., Voga, G., Grosek, Š. (ur.), Intenzivna medicina: učbenik. Ljubljana: Slovensko združenje za intenzivno medicino (SZIM), str. 991–997.

Strokovni članki

- Avsec, D. (2019). Pravni in organizacijski vidiki transplantacijske dejavnosti v Sloveniji. V Buturović-Ponikvar, J. (ur.), Zbornik predavanj strokovnega simpozija Etični izzivi pri transplantaciji organov (str. 45–53). Ljubljana: Univerzitetni klinični center Ljubljana.
- Gadžijev, A. (2019). Novi trendi v transplantacijski medicini – darovanje po zaustavitvi srca in sprejem v enoto intenzivne terapije z namenom kasnejšega darovanja organov in tkiv. V Buturović-Ponikvar, J. (ur.), Zbornik predavanj strokovnega simpozija Etični izzivi pri transplantaciji organov (str. 71–74). Ljubljana: Univerzitetni klinični center Ljubljana.
- Uštar, B. (2019). Donorska in transplantacijska dejavnost v letu 2018. Transplant: glasilo Slovenskega društva Transplant, junij 2019: 4–8.

- Uštar, B. (2019). Statistični podatki v letu 2019. Transplant: glasilo Slovenskega društva Transplant, december 2019: 4.
- Šimenc, J., Avsec, D. (2019). Eno leto od vzpostavitve elektronske opredelitve o posmrtnem darovanju organov in tkiv. Transplant: glasilo Slovenskega društva Transplant, december 2019 : 5–7.
- Šimenc, J., Avsec, D. (2019). Daj življenju priložnost. Ledvica: Glasilo Zveze društev ledvičnih bolnikov Slovenije, december (3): 5–6.
- Uštar, B. (avtor, ur.), Šimenc, J., Gadžijev, A., Čebulc, G., Jakovac, J., Avsec, D. (ur.). (2019). Daj življenju priložnost: donorska in transplantacijska dejavnost v Sloveniji v letu 2018. Ljubljana: Zavod RS za presaditve organov in tkiv Slovenija-transplant. Dostopno tudi na: http://www.slovenija-transplant.si/uploads/media/TRANSPLANT_BROSURA__2018_SLO_EN.pdf.
- Darovanje organov in tkiv za namen zdravljenja. V Sotler, R. (ur.). Osnove prve pomoči: Priročnik za usposabljanje kandidatov za voznike motornih vozil. Ljubljana: Rdeči križ Slovenije, str. 198–199.

Predavanja na konferencah (v kronološkem redu)

- Šimenc, J.: The role of (new) media in raising social awareness in organ and tissue donation. Eudonorgan – Social awareness event, Budimpešta, 14. 1. 2019.
- Šimenc, J., Avsec, D.: Creating good reputation on Facebook: the case of Slovenia-transplant. 5th ELPAT congress Developing dialogue, pioneering practice, Krakow, 26.–29. 4. 2019.
- Avsec, D.: Obstacles in transplant medicine in the ICU. 28. Mednarodni simpozij intenzivne medicine, Bled, 31. 5.–1. 6. 2019.

- Gadžijev, A.: New trends in transplant medicine. 28. Mednarodni simpozij intenzivne medicine, Bled, 31. 5.–1. 6. 2019.
- Šimenc, J.: Social media as a tool to inform publics on organ donation. 28. Mednarodni simpozij intenzivne medicine, Bled, 31. 5.–1. 6. 2019.
- Avsec, D.: Organizacijski in pravni okvir transplantacije organov v Sloveniji. Etični izzivi pri transplantaciji organov, UKC Ljubljana, Ljubljana, 7. 6. 2019.
- Gadžijev, A.: Srčna in cirkulacijska smrt. Etični izzivi pri transplantaciji organov, UKC Ljubljana, Ljubljana, 7. 6. 2019.
- Uštar, B., Avsec, D.: Introducing E-registration in Slovene donor registry. 19th ESOT congress Inspiring minds, driving progress, Kopenhagen, 15.–19. 9. 2019.
- Avsec, D. & Kušar, B.: Slovenija-transplant – primer dobre prakse. Microcop IT konferenca, Brdo pri Kranju, 15. 10. 2019.
- Šimenc, J. & Avsec, D.: Medicinska antropologija v medicinski praksi (vabljeno predavanje). Zdravje in družba: Interdisciplinarno raziskovanje zdravja, bolezni in zdravljenja (znanstvena konferenca ob 100-letnici UL), Filozofska fakulteta Univerze v Ljubljani, Ljubljana, 24. 10. 2019.
- Avsec, D.: General aspects of organ donation and transplantation; Communication in the ICU and Declaration of Death; Public Education on Organ Donation 3rd International Training Course in Transplant Coordination, Istanbul, 25.–29. 11. 2019.
- Šimenc, J.: Using digital media tools for donation professionals. 3rd International Training Course in Transplant Coordination, Istanbul, 25.–29. 11. 2019.
- Avsec, D.: Social significance of organ donation (vabljeno predavanje). China International Organ Donation Conference, Kunming (Kitajska), 7. 12. 2019.

INTERDISCIPLINARNI SIMPOZIJ O DAROVANJU ORGANOV
V OKVIRU PROJEKTA **EUDONORGAN**

FOTO: Eudonorgan

VIRI

- Spletna stran Zavoda Slovenija-transplant: http://www.slovenija-transplant.si/.
- Spletna stran Zavoda RS za transfuzijsko medicino: http://www.ztm.si/register-darovalcev/slovenija-donor/.
- Zakon o pridobivanju in presaditvi delov človeškega telesa zaradi zdravljenja (ZPPDČT), Ur. l. RS, št. 56/2015.
- Council of Europe Convention against Trafficking in Human Organs (CM, 9. 7. 2014).
- Spletna stran Eurotransplanta: http://www.eurotransplant.org/cms/.
- Spletna stran European Directorate for the Quality of Medicines and Healthcare EDQM: https://www.edqm.eu/.
- Guide to the Quality and Safety of Organs for Transplantation. European Committee (Partial Agreement) on Organ Transplantation (CD-P-TO), European Directorate for the Quality of Medicines & Health Care, Strasbourg; 7th ed. 2018.
- Guide to the Quality and Safety of Tissues and Cells for human application. European Committee (Partial Agreement) on Organ Transplantation (CD-P-TO), European Directorate for the Quality of Medicines & Health Care, Strasbourg; 4th ed. 2019.
- The Madrid Resolution on Organ Donation and Transplantation: https://www.edqm.eu/sites/default/files/article_the_madrid_resolution_on_organ_donation_and_transplantation_transplantation_journal_june_2011.pdf.
- Razvoj Transplantacijske medicine v Sloveniji: programi, smernice in perspektive. Urednici Danica Avsec in Zvonka Zupanič Slavec; ilustracije Radko Oketič. Ljubljana: Zavod RS za presaditve organov in tkiv Slovenija-transplant; Celje: Celjska Mohorjeva družba: Društvo Mohorjeva družba, 2016.
- Donorski program: Postopki za izvajanje v donorskih bolnišnicah. Avtorji: Andrej Gadžijev, Danica Avsec. Ljubljana: Zavod RS za presaditve organov in tkiv Slovenija-transplant. Ljubljana, 2018.
- Preliminary numbers 2019, IRODaT (International Registry in Organ Donation and Transplantation), www.irodat.org.
- Spletna stran projekta EUDONORGAN: http://eudonorgan.eu/.
- Buturović-Ponikvar, J (ur.), Zbornik predavanj strokovnega simpozija Etični izzivi pri transplantaciji organov. Ljubljana: Univerzitetni klinični center Ljubljana.

Donation and transplantation activity in Slovenia in 2019

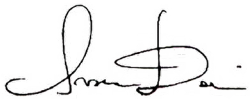
Introductory words

Our annual publication »Give Life a Chance« presents statistical data and key highlights of donation and transplantation activity in 2019. The data are set out clearly within the international context and a broader timeframe to ensure better understanding of the success achieved by the national programmes.

In the last year, all Eurotransplant member countries saw a slight downward trend in their donation and transplantation programmes. The reorganisation of organ allocation has unexpectedly had negatively effects for small countries like Slovenia. The biggest decline was observed in the kidney transplant programme, although there were plans to eliminate deficiencies in early 2020. Nevertheless, we have seen amazing achievements in the lung and heart transplant programmes. Moreover, with 21.14 donors per million people, Slovenia is still classified among the top countries in terms of its deceased donation programme.

Every instance of donation and transplantation reminds us once again such treatment is very complex and can only be provided based on a collective, well-coordinated and comprehensive approach. I would like to thank all the donor centres, transplantation teams and all the visible and less visible members, including every donor who has participated or is participating in the national donor and recipient programme.

You are warmly invited to read our publication, which is intended for the broadest readership.



Chief Phys. Danica Avsec, MD, Councillor,
Director of the Slovenija-transplant Institute and responsible physician for donation activity

The Slovenija-transplant institute

Since 2002 the Institute of the Republic of Slovenia for the Transplantation of Organs and Tissues Slovenija-transplant has been the central national expert institution for connecting, co-ordinating, promoting and supervising donation and transplant activity in Slovenia. Established in 1998, Slovenija-transplant is the primary co-ordination office of the national transplantation network. The national network consists of 11 donor hospitals across Slovenia, the Transplantation Centre at the Ljubljana University Medical Centre, and the Tissue Typing Centre within the Blood Transfusion Centre of Slovenia. It operates the donor and recipient programme, while also ensuring that medical treatment with organ transplantation is possible for all who need it. The national network operates continuously and its expert teams are in a state of readiness 24 hours a day, every day of the year.

Since 2000 Slovenia has been a member of Eurotransplant, a non-profit organisation for organ and tissue exchange. After meeting the demanding entry criteria, it was the first country in the region to join the group of five successful countries in the area of transplantation, i.e. Germany, Austria, Belgium, Luxembourg and the Netherlands. In 2002, Slovenija-transplant signed a co-operation agreement with Eurotransplant. Today, Eurotransplant, with its registered seat in Leiden in the Netherlands, brings together 8 countries and over 137 million inhabitants. This membership is important for our patients because, upon joining Eurotransplant, the chances of their survival and transplant treatment outcomes have improved considerably, especially for life-threatening conditions like acute heart and liver failure and other special cases (e.g. children, hypersensitive patients). Thanks to our co-operation, the waiting lists have been shortened significantly, the national transplant programmes are fully operating and we have also introduced combined transplants. First and foremost, we have been able to ensure greater donor–recipient tissue compatibility. Tissue incompatibility can make finding an appropriate organ for certain patients impossible in Slovenia. In 2020, we plan to celebrate our impressive 20th anniversary of our successful co-operation with Eurotransplant by organising a series of events.

Since being established, the Institute has been constantly developing in line with international guidelines. We strive to create an educated and motivated professionals and, by way of multi-pronged communication, consistently increase the public's trust in transplantation medicine. Our membership in international professional committees and participation in European projects has given us an equal footing in the international arena, including as active co-creators of strategies, development and expert training in international donation and transplant activities. We continue to set an internationally recognised example of how a national donor programme should be organised and managed.

In its management and leadership of activities for procuring and using parts of the human body for medical treatment purposes, Slovenija-transplant consistently complies with the legislation, European directives and adopted international conventions. We ensure that national legislation and expert protocols are promptly updated. Any changes we introduce are based on unanimously adopted expert decisions, critical social considerations as well as the principles of medical ethics and deontology.

The key guidelines of our Institute's operations include: self-sufficiency | patient equality and safety | optimal effectiveness | quality | traceability | professionalism | non-commercialism | transparency | voluntary donation | prevention of abuse.

Since being established, Slovenia-transplant's Director has been Chief Phys. Danica Avsec, MD, Councillor and the responsible physician for donation activity. The Institute operates under the auspices of the Ministry of the Republic of Slovenia for Health. In 2019, the Institute employed 9 full-time staff and was cooperating with 102 people under contract in the donation programme.

www.slovenija-transplant.si

@SloTransplant

Achievements and highlights of 2019

10,000 on the register of designated persons

At the end of the year, almost 10,000 people were included on the register of designated after--death organ and tissue donors. By the first days of January 2020, this figure had already been exceeded. In early January, designated persons register included 10,137 people, accounting for 0.57% of the population older than 15 years. In 2020, we will continue our activities of raising the general public's awareness and encouraging people to become designated donors, with a stress on electronic channels via the *www.e-uprava.si* portal. The possibility of submitting a statement for or against organ donation through the eAdministration web portal was introduced in November 2018 so as to simplify the procedure. The next year, 566 people had registered electronically, slightly less than one-half of all designations made in 2019.

National lung transplant programme sees outstanding results at the Ljubljana University Medical Centre

In 2019, the excellent multidisciplinary team in the national programme for lung transplant treatment accomplished extraordinary results. After the programme was revived last year in the Transplantation Centre of the Ljubljana UMC, 10 complex transplantations of both lung lobes were successfully performed, whereas in one case the transplantation for a Slovenian paediatric patient was performed by the Vienna University Medical Centre. In all cases, patient preparation before the lung transplant and post-operative care are always performed by relevant departments of the Ljubljana UMC. We would like to congratulate everyone involved for their outstanding work!

100% consent for donation and 10 actual donors at the Maribor University Medical Centre

In 2019, the team of the Maribor UMC donor hospital, with 13 potential and 10 actual donors, continued its good work within the national donor network. Of eight (utilised) donors, at least one organ was transplanted. Above-average results were also achieved in terms of 100-percent approval by relatives of the deceased person about donation. We wish to thank all of our colleagues in the donor programme for their commitment and congratulate them on their outstanding work!

Successfully completed EUDONORGAN EU project

In 2019, we successfully completed our participation in the 3-year European EUDONORGAN project *(Training and social awareness for increasing organ donation in the European Union and neighbouring countries)*, financed by the European Commission under a special agreement. The project's purpose was attained, namely the promotion of a positive attitude among society to organ donation, multidisciplinary and regional connections among all stakeholders as well as a comparison of good practices. Besides organisations from Spain, Croatia and Italy, Slovenija-transplant was the key partner in the project which encompassed activities aimed at educating health professionals and raising awareness among the general public. Two interdisciplinary symposiums on organ donation led by Slovenija-transplant were organised in 2019, in Budapest and Stockholm. We actively participated in the central seminar in the European Parliament in Brussels, addressing political authorities. It became clear just how important international connections are for the promotion of organ donation. Joint campaigns bring about more practical and visible results, although there are still too many individual activities at the local level whose effects later fade away.

About donor medicine at the international symposium on intensive care medicine

With a theme-based set on donation medicine, on 1 June 2019 members of Slovenija-transplant participated at the 28th international symposium on intensive care medicine held in Bled, Slovenia, and organised by the Slovenian Association of Intensive Care Medicine. Together with colleagues from Poland and Croatia, we presented the applicable work guidelines, the biggest obstacles to transplant activity in intensive care units and the possibilities for developing a national deceased donation programme, among others, the donation after circulatory death.

Findings of the »Social Aspects of Organ Donation in Practice« research project

Which impediments do people face when deciding whether to declare as a donor given that 85% of them declarately support treatment with organ transplantation? How to encourage the public to actively declare as donors and speak about it? Which public awareness strategies are the most successful? These are some of the key questions we sought answers to in the applied research project “Social Aspects of Organ Donation” (co-financed by the *Slovenian Research Agency* – ARRS) in co-operation with the Faculty of Social Sciences at the University of Ljubljana, and the National Institute of Public Health. Countrywide field research about views on organ donation was conducted and recommendations for public communication issued (see Berzelak, Avsec, Kamin 2019). The project was successfully completed and the latest research findings and results included in our communication activities.

Education and certification of European transplant coordinators (CETC)

Chief Phys. Danica Avsec, as President of the international *Board of Transplant Co-ordinators* (BTC), which operates under the auspices of the European *UEMS Surgery*, organised in co-operation with the *Turkish Transplant Foundation* a preparatory course for an exam for the certification of European transplant co-ordinators (CETC). The course was run on 1 and 2 August 2019

in Istanbul. Chief Phys. Danica Avsec and Andrej Gadžijev gave the lectures. The course was also attended by two Slovenian CETC candidates who later passed the exam with flying colours. The exam was held on 14 September in Copenhagen as part of the European Society for Organ Transplantation (ESOT) congress.

On ethical issues in transplantation medicine

On 7 June 2019, an international symposium called »Ethical Challenges in Organ Transplantation« was organised on the premises of the Ljubljana UMC. A number of bad practices from abroad were brought to light at the event. In our papers, written by Chief Phys. Danica Avsec and Andrej Gadžijev, we presented Slovenija-transplant's priority areas, including the ethical bases and guidelines we observe while combating trafficking and introducing changes to donation programmes. We demonstrated how good organisation and compliance with high ethical criteria underpin safe, high-quality and transparent transplantation treatment. In Slovenia, any abuse of the system is excluded and criminally prosecuted. Chief Phys. Avsec is an active member of international bodies, thereby contributing to the prosecution of inadmissible violations of human rights in the form of trafficking in human organs as well as to a more ethical stance in the global transplantation community.

Key statistics for 2019

On 31 December 2019, there were **156 PATIENTS ON THE OVERALL WAITING LIST:**

- **42 for a heart**;
- **95 for a kidney transplant** (of whom one in combination with a liver transplant and one in combination with a pancreas transplant);
- **17 for a liver transplant** (of whom one in combination with a kidney transplant);
- **one for a pancreas** (in combination with a kidney) transplant.

AVERAGE WAITING PERIOD:

- **247 days for a heart transplant** (urgent transplantation: 50 days);
- **about 300 days for a kidney** and
- **254 days for a liver transplant.**

1.254 PEOPLE REGISTERED ON THE NATIONAL REGISTER of designated persons (9 of whom were against donation).

There were **44 actual deceased donors** and **38 utilised deceased donors**, from whom **132 ORGANS WERE PROCURED.**

THE TRANSPLANTATION CENTRE OF THE LJUBLJANA UMC TRANSPLANTED 95 ORGANS:

- 38 kidneys,
- 22 hearts,
- 24 livers,
- 10 lungs and
- 1 pancreas.

THE CONSENT RATE for donation **was high, i.e. 78%**. This figure reveals the high level of support among the general public.

Solid organs

NATIONAL WAITING LIST FOR ORGAN TRANSPLANTATION

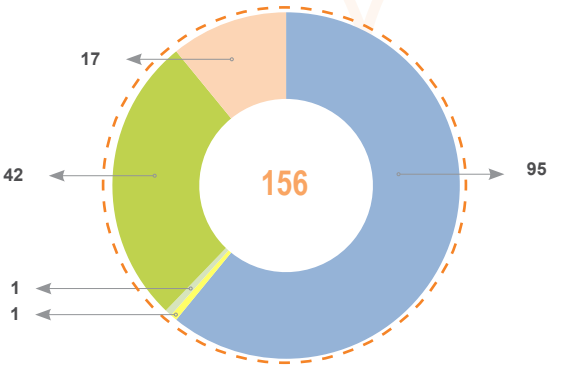
The waiting list is a list of patients in need for a medical treatment with organ transplantation. The indications for transplantation are specific to each organ/tissue/cell. All patients in the Republic of Slovenia have the same possibility of being included on the list of recipients and have equal access to the transplantation. By the end of 2019, 156 patients were waiting for an organ transplant, namely the highest number thus far, mostly due to more patients waiting for a kidney transplant. The average waiting period for all organs is relatively short compared to other countries. On average, Slovenian patients wait for a heart, liver or kidney transplant for less than 1 year.

In 2019, 134 Slovenian patients were added on the waiting list: 80 for a kidney, 27 for a heart and 27 for a liver transplant.

Status of the national waiting list on 31.12.2019 (patients with active status)

Kidney	Kidney and pancreas	Kidney and liver	Heart
95	1	1	42
Heart and liver	**Heart and kidney**	**Liver**	**Pancreas**
0	0	17	0
TOTAL			**156 patients**

Source: http://statistics.eurotransplant.org/

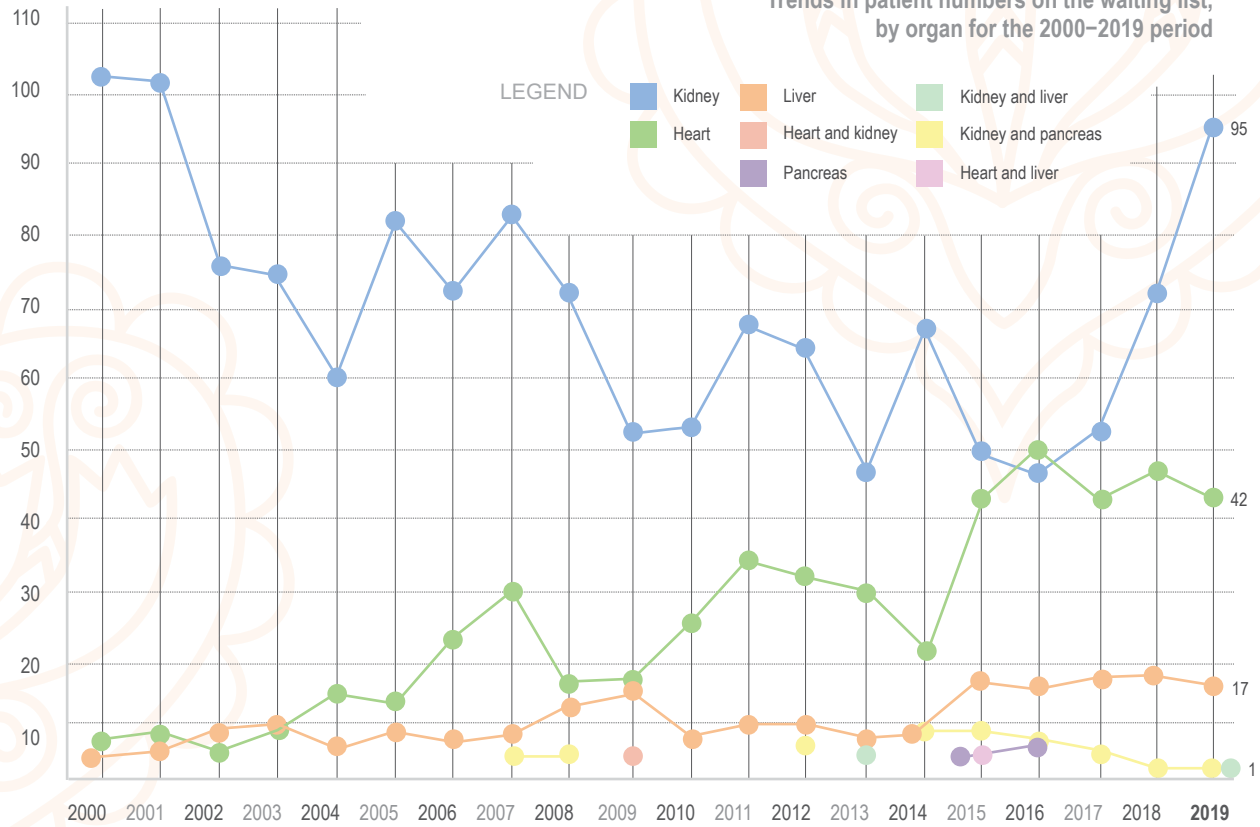


Status of the national waiting list in the 2000–2019 period (on 31.12.)

Year	Kidney	Kidney and pancreas	Kidney and liver	Heart	Heart and liver	Heart and kidny	Liver	Pancreas	TOTAL
2000	102			7			2		111
2001	101			8			4		113
2002	76			2			7		85
2003	75			9			8		92
2004	60			15			4		79
2005	81			14			9		104
2006	72			24			6		102
2007	83	1		30			9		123
2008	71	1		17			13		102
2009	52			18		1	15		86
2010	53			26			8		87
2011	68			34			10		112
2012	65	2		32			10		109
2013	47		1	30			7		85
2014	69	8		21			9		107
2015	50	8		42	1		18	1	120
2016	47	3		50			17	2	119
2017	51	2		42			18		113
2018	72	1		48			19		140
2019	95	1	1	42			17		156

Source: http://statistics.eurotransplant.org/

Trends in patient numbers on the waiting list, by organ for the 2000–2019 period



NUMBER OF DECEASED DONORS

In 2019, Slovenian donor hospitals acquired 44 actual deceased donors* who were medically suitable and for whom consent had been obtained from their relatives. Data at the beginning show the number of actual deceased donors in Slovenia compared to other countries around the world. Below are details on the number of utilised deceased donors*, which means that at least one organ was transplanted from each donor. Compared to other Eurotransplant members, in 2019 Slovenia was again ranked fourth in terms of the number of utilised deceased donors per million people.

Number of actual deceased donors (DD) per million people (PMP) in Slovenia in 2019 and a comparison with other countries

Country	No. of DD/PMP 2019
1. Spain	48,9
2. ZDA	36,88
3. Croatia	34,63
4. Portugal*	33,63
5. France	33,25
6. Belgium	30,4
7. Czech Republic	27
8. Finland	26,36
9. Belrus	26,2
10. Malta*	25

Country	No. of DD/PMP 2019
11. England	24,88
12. Italy	24,7
13. Austria	23,8
14. Urugvay	22,86
15. Avstralia*	22,17
16.Slovenija	21,14
17. *Canada**	20,56
18. Argentina*	19,6
19. Island	19,29
20. Sweden	19

Country	No. of DD/PMP 2019
21. Estonia	18,8
22. Norway	18,78
23. Lithuania	18,7
24. Hungary	18,42
25. Switzerland	18,4
26. Ireland	17,35
27. Denmark	17,25
28. Brazil*	16,73
29. Netherlands	14,93
30. Slovakia*	14,35

* Data from 2018, ** Total utilized donors

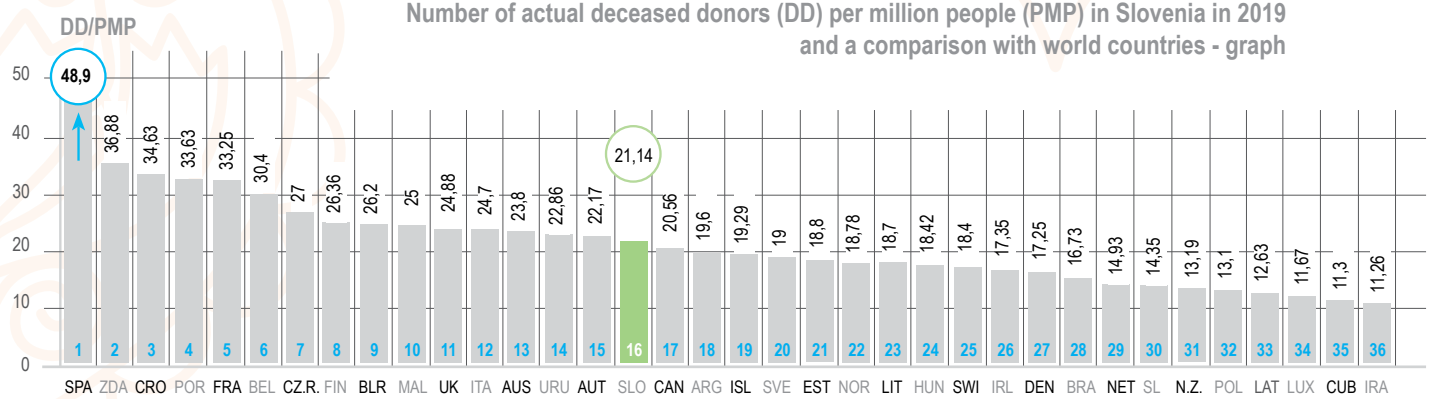
Country	No. of DD/PMP 2019
31. New Zealand*	13,19
32. Poland	13,1
33. Latvia*	12,63
34. Luksenbourg*	11,67
35. Cuba*	11,3
36. Iran*	11,26
37. Germany	11,2

Country	No. of DD/PMP 2019
38. Israel	10,8
39. Chile	10,4
40. South Korea	8,68
41. Columbia*	8,04
42. Ecuador*	7,87
43. Turkey	7,54
44. Costarika*	7

Country	No. of DD/PMP 2019
45. Cyprus	6,86
46. Kuwait	6,75
47. Greece	5,5
48. Rusia*	4,49
49. China*	4,43
50. Mexico*	4,39
51. Moldova	4,1

* Data from 2018

Number of actual deceased donors (DD) per million people (PMP) in Slovenia in 2019 and a comparison with world countries - graph



Country	No. of DD/PMP 2019
52. Hong Kong	3,86
53. Saudi Arabia	3,77
54. Bulgaria	3,71
55. Thailand	3,66
56. Romania*	3,32
57. Quatar*	2,59
58. Peru	2,3

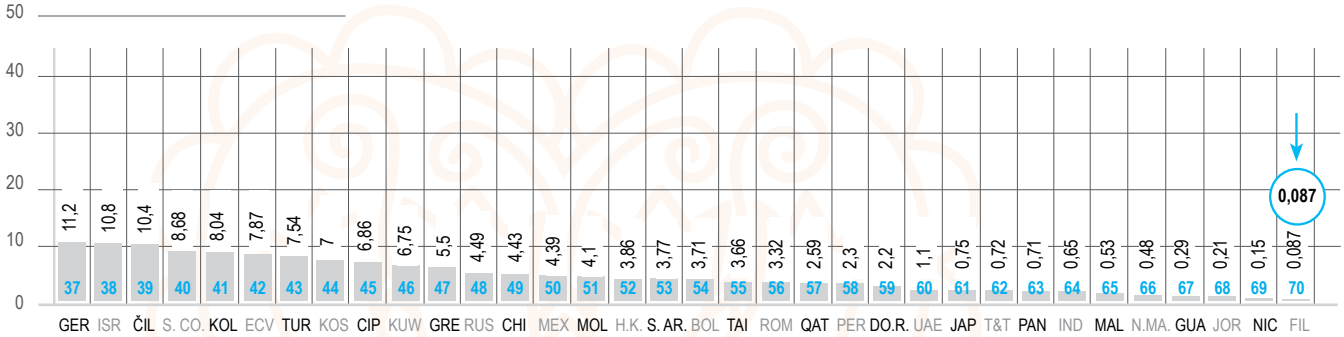
Country	No. of DD/PMP 2019
59. Dominic. republic	2,2
60. UAE*	1,1
61. Japon*	0,75
62. Trinidad & Tobago*	0,72
63. Panama*	0,71
64. India*	0,65
65. Malaysia	0,53

Country	No. of DD/PMP 2019
66. North Macedonia*	0,48
67. Gvatemala*	0,29
68. Jordania*	0,21
69. Nicaragua*	0,15
70. Filipins	0,087

* Data from 2018

Source: IRODaT (International Registry in Organ Donation and Transplantation) www.irodat.org
Preliminary numbers 2019

DD/PMP

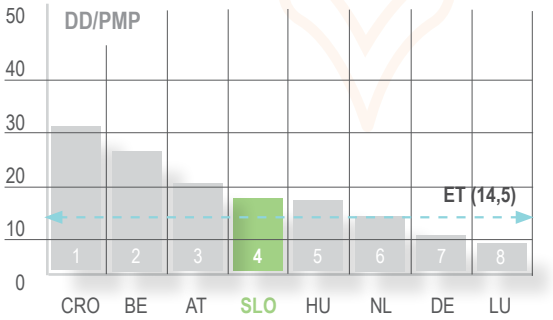


Number of utilised deceased donors (DD) per million people (PMP) in Slovenia in 2019 and a comparison with all Eurotransplant countries

Country	Slovenia (SLO)	Eurotransplant (ET)
Number of DD	38	2.042
DD/PMP	18,3	14,5

Number of utilised deceased donors per million people (DD/PMP) and a comparison with other Eurotransplant countries in 2019

ET Country	Number of DD/PMP in 2019
1. Croatia (CRO)	31,4
2. Belgium(BE)	27,2
3. Avstria (AT)	20,3
4. Slovenia (SLO)	18,3
5. Hungary (HU)	18,2
6. Netherlands (NL)	14,5
7. Germany (DE)	10,8
8. Luxembourg (LU)	8,1



Source: http://statistics.eurotransplant.org/

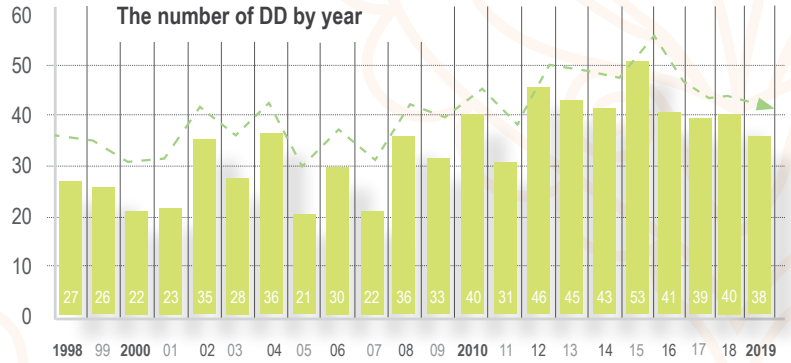
Number of utilised deceased donors (DD) and number of utilised deceased donors per million people (DD/PMP) in Slovenia in the 1998–2019 period

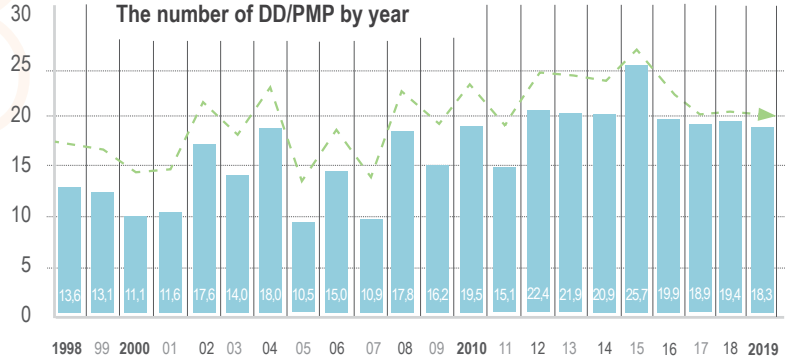
Year	Number of DD	Number of DD/PMP
1998	27	13,6
1999	26	13,1
2000	22	11,1
2001	23	11,6
2002	35	17,6
2003	28	14
2004	36	18
2005	21	10,5
2006	30	15
2007	22	10,9
2008	36	17,8
2009	33	16,2
2010	40	19,5

Year	Number of DD	Number of DD/PMP
2011	31	15,1
2012	46	22,4
2013	45	21,9
2014	43	20,9
2015	53	25,7
2016	41	19,9
2017	39	18,9
2018	40	19,4
2019	38	18,3
TOTAL	755	16,9

Source: http://statistics.eurotransplant.org/

Number of utilized deceased donors (DD) and number of utilized deceased donors per million people (DD/PMP) in Slovenia in the 1998–2019 period





* The critical Pathway for Organ Donation

POSSIBLE DECEASED ORGAN DONOR
A patient with a devastating brain injury or lesion OR a patient with circulatory failure AND apparently medically suitable for organ donation

Donation after Circulatory Death (DCD)	Treating physician to Identify/refer a potential donor	Donation after BrainDeath (DBD)
POTENTIAL DCD DONOR **a.** A person whose circulatory and respiratory functions have ceased and resuscitative measures are not to be attempted or continued. OR **b.** A person in whom the cessation of circulatory and respiratory functions is anticipated to occur within a time frame that will enable organ recovery.	**Reasons why a potential donor does not become a utilized donor** **SYSTEM** - Failure to identify/refer a potential or eligible donor - Brain death diagnosis not confirmed (e.g. does not fulfil criteria) or completed (e.g. lack of tehnical resources or clinician to make diagnosis or perform confirmatory tests) - Circulatory death not declared within the appropriate time frame - Logistical problems (e.g. no recovery team) - Lack of appropriate recipient (e.g. child, blood type, serology positive) **DONOR/ORGAN** - Medical unsuitability (e.g. serology positive, neoplasia) - Haemodynamic instability/unanticipated cardiac arrest - Anatomical, histological and/or functional abnormalities of organs - Organs damaged during recovery - Inadequate perfusion of organs or thrombosis **PERMISSION** - Expressed intent of deceased not to be donor - Relative's refusal of permission for organ donation - Refusal by coroner or other judical officer to allow donation for forensic reasons	POTENTIAL DBD DONOR A person whose clinical condition is suspected to fulfill brain death criteria.
ELIGIBLE DCD DONOR A medicaly suitable person who has been declared dead based on the irreversible absence of circulatory and respiratory functions as stipulated by the law of the relevant jurisdiction within a time frame that enables organ recovery.		ELIGIBLE DBD DONOR A medicaly suitable person who has been declared dead based on neurologic criteria as stipulated by the law of the relevant jurisdiction.
ACTUAL DCD DONOR A consented eligible donor: **a.** In whom an operative incision was made with the intent of organ recovery for the purpose of transplantation. OR **b.** From whom at least one organ was recovered for the purpose of transplantation.		ACTUAL DBD DONOR A consented eligible donor: **a.**In whom an operative incision was made with the intent of organ recovery for the prupose of transplantation. OR **b.** From whom at least one organ was recovered for the purpose of transplantation.
UTILIZED DCD DONOR An actual donor from whom at least one organ was transplanted.		UTILIZED DBD DONOR An actual donor from whom at least one organ was transplanted.

The »dead donor rule« must be respected. That is, patients may only become donors after death, and the recovery of organs must not couse a donor´s death.

Source: The Madrid Resolution on Organ Donation and Transplantation

REGISTER FOR DONATION DECLARATIONS

Every Slovenian citizen has the right and possibility during their lifetime to decide to donate their organs and tissues. This decision is formally confirmed when it is entered in the national register of designated persons, set up back in 2004.
The donor statement may be signed at many authorised donor registration points around Slovenia (a detailed list is published at *www.slovenija-transplant.si)* or electronically using a digital signature on the eAdministration portal (https://e-uprava.gov.si/). Since June 2017, a declaration against making organ donation is also possible.

In 2019, we collected a total of 1.254 declarations (1.245 FOR and 9 AGAINST), of which 566 were submitted electronically. As at 31.12.2019, 9.869 declarations were listed in the register (9.855 FOR and 14 AGAINST).

Number of declarations in the register, by year, in the 2004–2019 period

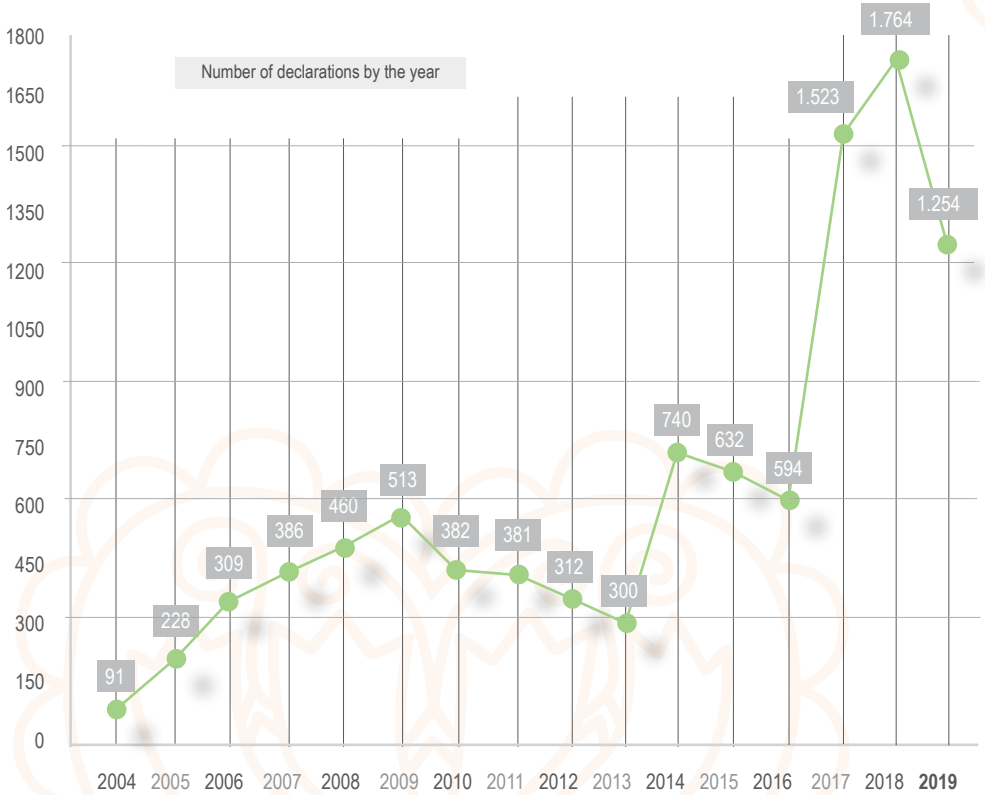
Year	No. of declarations
2004	
2005	228
2006	309
2007	386
2008	460
2009	513

Year	No. of declarations
2010	382
2011	381
2012	312
2013	300
2014	740
2015	632

Year	No. of declarations
2016	594
2017	1.523
2018	1.764
2019	1.254
TOTAL	9.869

Source: archive of Slovenija-transplant

Number of declarations regarding donation in the register, by year, in the 2004–2019 period



PERCENTAGE OF DONATION REFUSALS

A conversation about donation with the close relatives of a potential deceased donor (PDD) is conducted in every case when the donation of organs for transplantation is feasible. It is only after the death has been confirmed and the time of death registered that the transplantation co-ordinator checks the register to see whether the deceased was a designated after-death donor. Despite knowing about the designation, the central transplantation co-ordinator always holds a conversation with the deceased person's close relatives about donation. During this conversation, they try to find out what the deceased person's position was regarding after-death organ donation.

If their intention is unknown, the close relatives make the decision. All procedures are carried out with a high level of sensitivity, understanding of the extremely difficult emotional circumstances and in line with the legislative provisions and the medical doctrine. In 2019, the rate of refusals was significantly lower than in 2018. Donation was refused by 23% of such relatives.

As the death of a close relative is a difficult experience for anyone, Slovenija-transplant offers the donor's relatives an opportunity to be given grief counselling by a professionally trained and experienced expert.

Percentage of donation refusals in the 1998–2019 period

Source: archive Slovenija-transplant

Year	%
1998	21
1999	30
2000	37
2001	36

Year	%
2002	22
2003	23
2004	30
2005	19

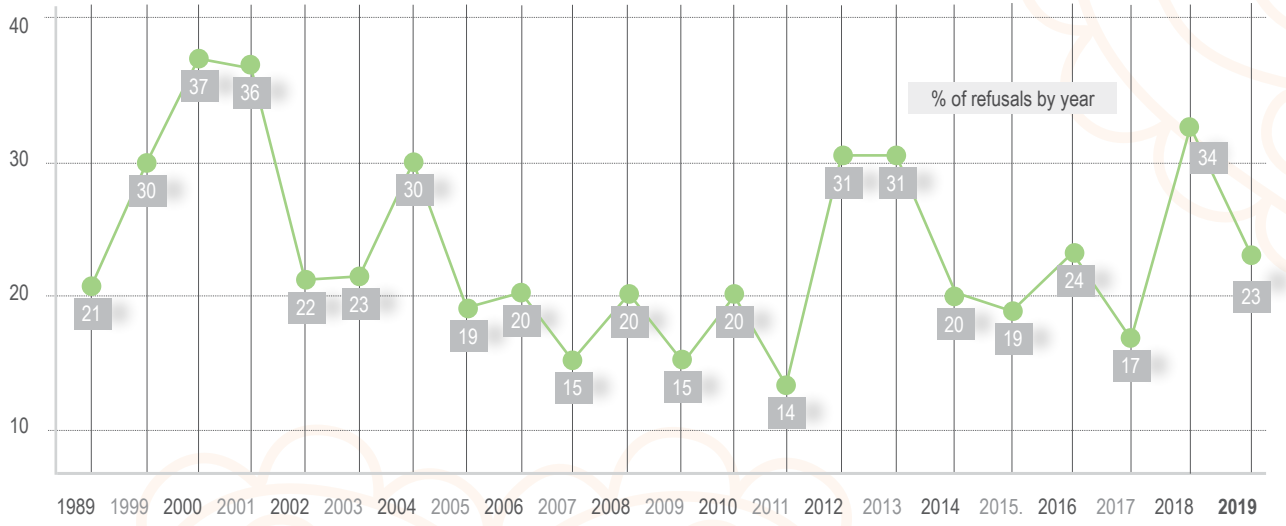
Year	%
2006	20
2007	15
2008	20
2009	15

Year	%
2010	20
2011	14
2012	31
2013	31

Year	%
2014	20
2015	19
2016	24
2017	17

Year	%
2018	34
2019	23

Percentage of donation refusals in the 1998–2019 period



OPERATIONS OF THE DONOR CENTRES

Eleven donor hospitals or centres are active in the Slovenian donation programme: the Ljubljana UMC and Maribor UMC and the general hospitals in Celje, Murska Sobota, Nova Gorica, Izola, Ptuj, Novo mesto, Slovenj Gradec, Jesenice and Brežice.

The following activities are performed in a donor centre:

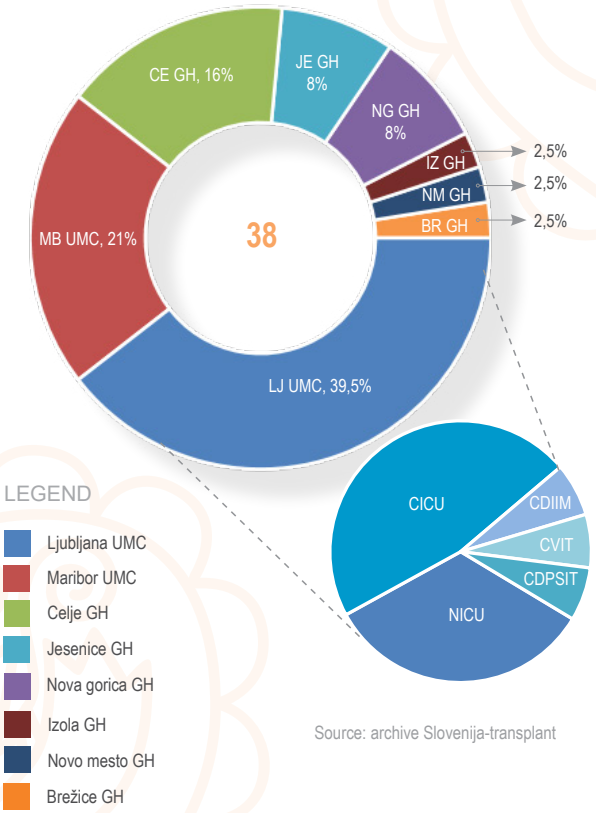
- identifying potential deceased donors;
- performing diagnostics of brain death;
- establishing the suitability of organs and tissues for removal and transplantation;
- informing the deceased person's close relatives about the possibility of organ donation and obtaining their consent;
- preserving the functioning of deceased donors' organs – in intensive care and during organ removal; and
- participating in organ - and tissue-removal procedures performed by Slovenian and foreign teams of surgeons.

The highest number of donors is provided by the Ljubljana UMC with the greatest number of beds in intensive care units. In 2019, 15 utilised deceased donors were procured there. Good results were also achieved by the UMC Maribor where in 2019 they procured 8 utilised deceased donors (out of 10 actual donors) and by Celje GH with 6 utilised donors (out of 7 actual donors). Jesenice GH and Nova Gorica GH stood out among the smaller donor hospitals with 3 utilised donors each. Izola GH, Novo mesto GH and Brežice GH each procured one utilised deceased donor in 2019.

Number and share of utilised deceased donors in individual donor centres (DC) in 2019

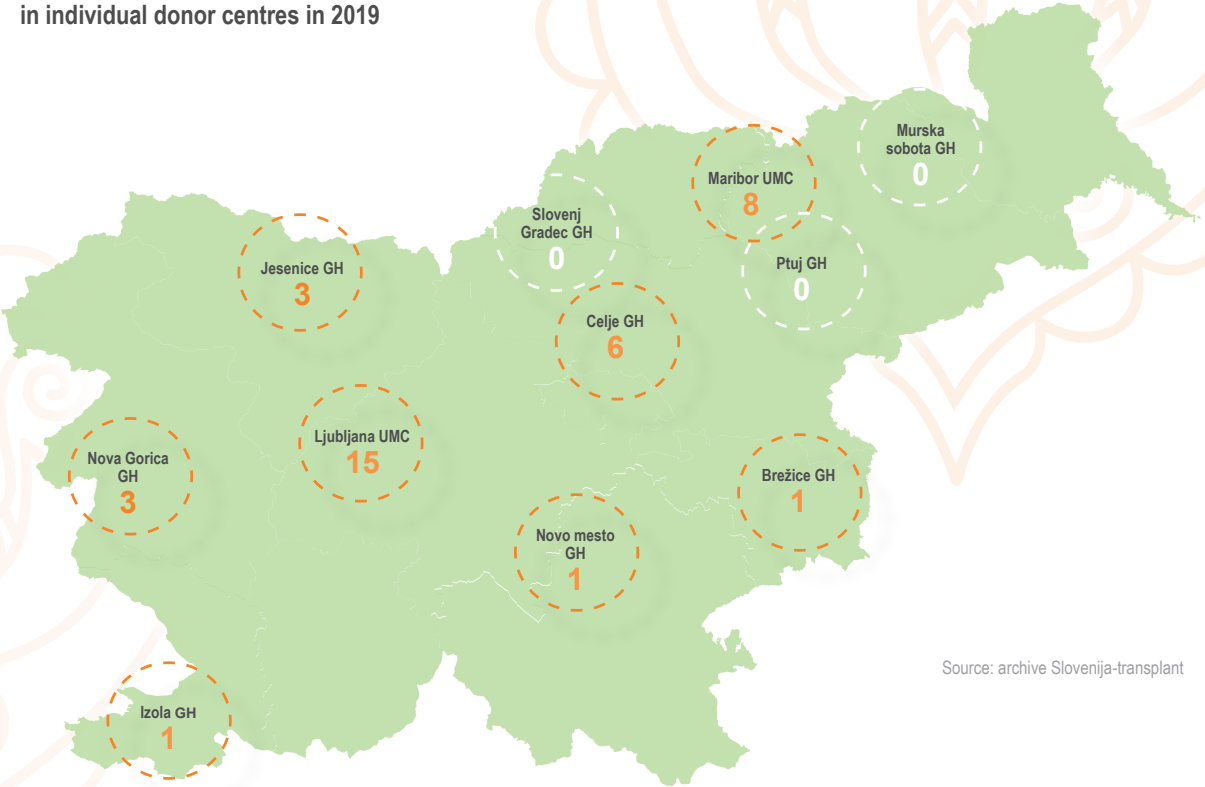
Donor centre	Number of DD	Share in %
Ljubljana UMC TOTAL	15	39,5
of which NICU*	5	
of which CICU	7	
of which CDIIM	1	
of which CVIT	1	
of which CDPSIT	1	
Maribor UMC	8	21
Celje GH	6	16
Jesenice GH	3	8
Nova Gorica GH	3	8
Izola GH	1	2,5
Novo mesto GH	1	2,5
Brežice GH	1	2,5
TOTAL	38	100

*NICU – Neurological Intensive Care Unit,
CICU – Central Intensive Care Unit,
CDIIM – Clinical Department of Internal Intensive Medicine,
CVIT – Cardio Vascular Intensive Therapy,
CDPSIT – Clinical Department of Paediatric Surgery and Intensive Therapy



Source: archive Slovenija-transplant

Number of utilized deceased donors in individual donor centres in 2019



Source: archive Slovenija-transplant

PREPARATORY COURSE FOR **EUROPEAN TRANSPLANT COORDINATION EXAM (CETC)**

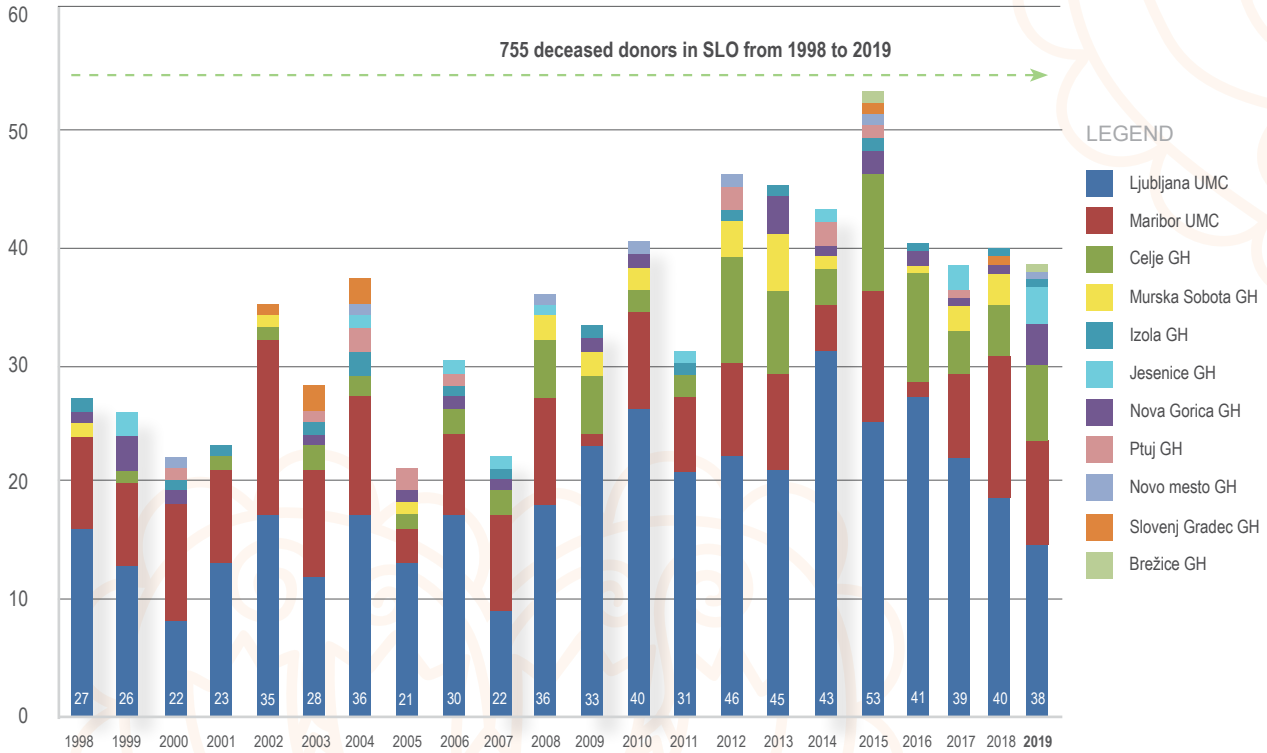
PHOTO: Slovenija-transplant

Number of utilised deceased donors in donor centres in the 1998–2019 period

Source: archive Slovenija-transplant

Year	LJ UMC	MB UMC	CE GH	MS GH	NG GH	Izola GH	Ptuj GH	Jesenice GH	NM GH	SG GH	Brežice GH
1998 / 99	16/13	8/7	0/1	1/0	1/3	1/0	0/0	0/2	0/0	0/0	0/0
2000	8	10			1	1	1		1		
2001	13	8	1			1					
2002	17	15	1	1						1	
2003	12	9	2		1	1	1			2	
2004	17	10	2			2	2	1	1	1	
2005	13	3	1	1	1		2				
2006	17	7	2		1	1	1	1			
2007	9	8	2		1	1		1			
2008	18	9	5	2				1	1		
2009	23	1	5	2	1	1					
2010	26	8	2	2	1				1		
2011	21	6	2			1		1			
2012	22	8	9	3		1	2		1		
2013	21	8	7	5	3	1					
2014	31	4	3	1	1		2	1			
2015	25	11	10		2	1	1		1	1	1
2016	28	2	7	1	2	1					
2017	22	7	4	2	1		1	2			
2018	18	13	4	2	1	1				1	
2019	15	8	6		3	1		3	1		1
TOTAL	405	170	76	23	24	16	13	13	7	6	2

Number of utilized deceased donors in donor centres in the 1998–2019 period



Potential and realisation in donor hospitals (analysis completed for 2018)

The donation potential of an individual donor hospital is expressed as the percentage share of brain-dead donors of the total number of deceased persons in the intensive care unit (ICU). It indicates the number of deaths where the diagnostic of brain death was completed. The potential is directly associated with the identification of eligible donors in ICUs.

Realisation in the donation process indicates the number of eligible donors (proven brain death) who became actual donors. It is expressed as the share of actual donors of the total number of deaths due to brain death in the ICUs.

Source: archive Slovenija-transplant

Donor hospital	All deaths in the ICU	PD	ED	*Potential (%)	Available (%)	AD	Realisation (%)	**Available (%)
Ljubljana UMC	389	83	46	11.8	13.7	18	39	65
Maribor UMC	284	56	25	8.8	13.7	17	68	65
Celje GH	131	39	11	8.4	8.3	7	64	55
Murska sobota GH	70	14	5	7.1	8.3	2	40	55
Nova Gorica GH	90	17	2	2.2	8.3	1	50	55
Novo mesto GH	143	9	4	2.8	8.3	0	0	55
Izola GH	60	9	1	1.6	8.3	1	100	55
Jesenice GH	52	7	2	3.8	8.3	1	50	55
Slovenj Gradec GH	55	8	1	1.8	8.3	1	100	55
Ptuj GH	72	8	0	/	8.3	0	/	55
Brežice GH	47	5	1	2.1	8.3	0	0	55

ICU – intensive care unit, **PD** – potential donor, **ED** – eligible donor (proven brain death), **AD** – actual donor (relatives' consent, organ removal)
Potential – % of brain-dead patients in total number of deceased persons in the ICU = % ED/total deaths in the ICU
Realisation – % of actual donors in total number of brain-dead patients = % AD/ED

*As expected, a donor hospital's potential is higher among hospitals which operate their own neurosurgical unit and can even reach up to 13.7 % (available potential). The Ljubljana UMC was quite close to its potential, whereas the Maribor UMC lagged behind its potential in 2018. In hospitals without their own neurosurgical unit, the available donation potential reaches up to 8.3 %. This figure was exceeded in 2018 by the Celje GH, while Murska Sobota GH was relatively close. Most donor hospitals still lagged behind the available values in 2018, which shows we can further improve in the area of identifying eligible donors.

Realisation mainly depends on the percentage share of absolute medical contraindications and refused donation by relatives in the period under scrutiny.

** Available realisation considers up to 20 % of absolute medical contraindications and up to 10 % of refused donation by relatives, while also distinguishing between donor hospitals with a neurosurgical unit and those without one (10 % difference); other obstacles in the donor process in total account for up to 5 %. Thus, the available realisation for hospitals with a neurosurgical unit was calculated at 65 % and for those without such a unit 55 %. In 2018, the available realisation was exceeded in the Maribor UMC, Celje GH, Izola GH and Slovenj Gradec GH. Some deviations were found in low values of the potential, e.g. in Izola GH and Slovenj Gradec GH, where 100 % realisation was achieved in one case – there were no medical contraindications for donation and the relatives gave their consent. In hospitals where there were no proven brain deaths in 2018 and no actual donors, the potential and the realisation were both 0 % or non-measurable (/).

List of authorised persons (i.e. hospital transplantation coordinators) in charge of the development, implementation and functioning of the donation programme in individual donor centres in 2019

Donor centre	Transplantation coordinators
Ljubljana UMC	Chief Phys. Rade Stanić, MD, MSc
Maribor UMC	Tanja Kuprivec, MD
Brežice GH	Nataša Pirc, MD
Celje GH	Barbara Hudournik, MD
Izola GH	Damjan Polh, MD
Jesenice GH	Andraž Nastran, MD
Murska Sobota GH	Chief Phys. Daniel Grabar, MD
Nova gorica GH	Edyta Čerkini, MD
Novo mesto GH	Matej Godnič, MD
Ptuj GH	Chief Phys. Majda Šarman, MD
Slovenj Gradec GH	Rok Popič, MD

WHY ORGAN DONATION MATTERS TO US ALL - **EUDONORGAN**
SOCIAL AWARENESS EVENT ON ORGAN DONATION

PHOTO: Eudonorgan

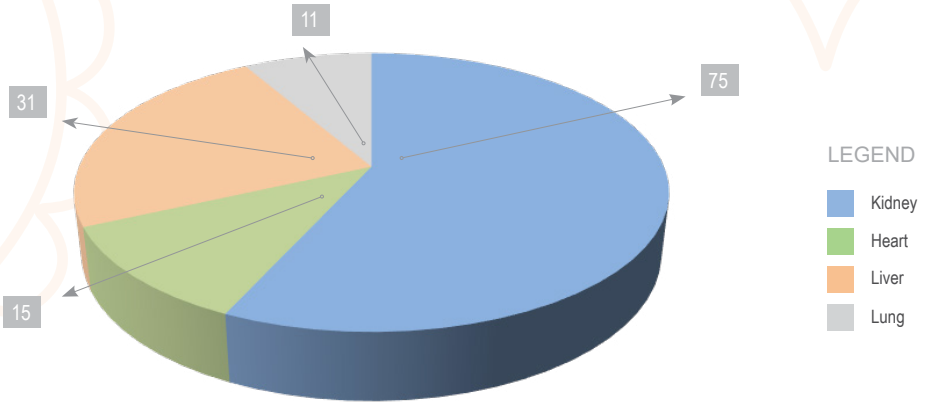
PROCURED SOLID ORGANS FOR THE PURPOSE OF MEDICAL TREATMENT

The number of procured organs depends on the number of procured deceased donors, along with the age and any medical contraindications. In 2019, the number of procured organs of deceased donors was slightly lower than the year before. Data for 2019 and a comparison with previous years are given below.

Number of procured organs of deceased donors in Slovenia in 2019

Kidney	Heart	Liver	Lung	Pancreas	TOTAL
75	15	31	11	0	132

Source: archive of Slovenija-transplant

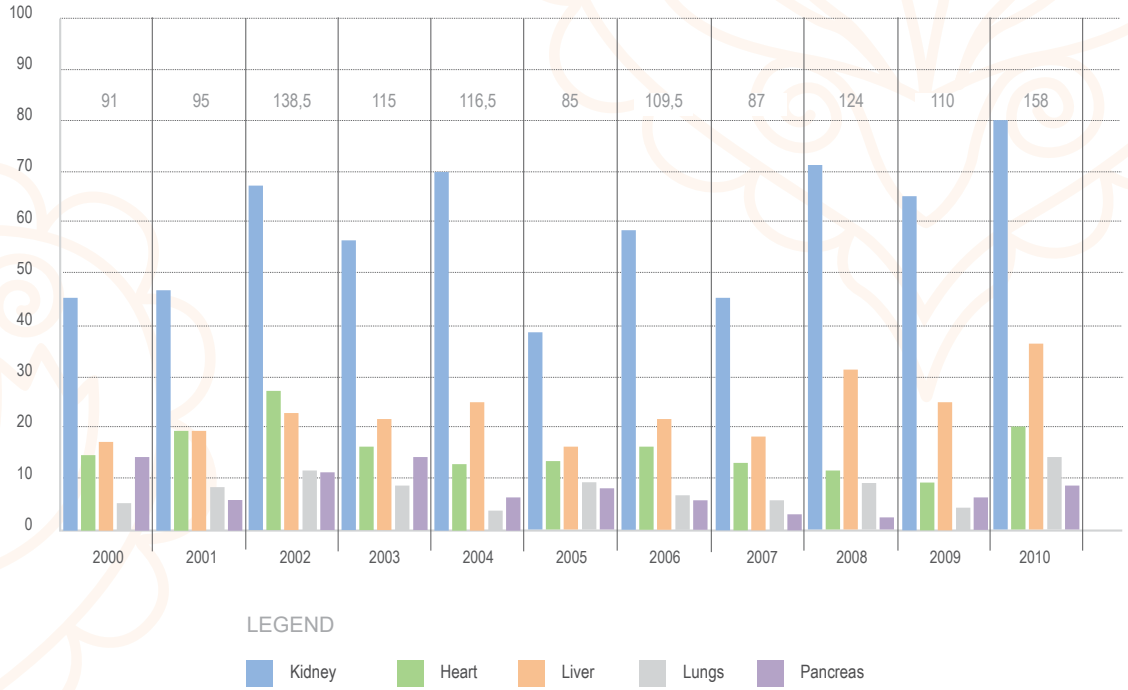


Procured organs of deceased donors in Slovenia in the 2000–2019 period

Source: archive of Slovenija-transplant

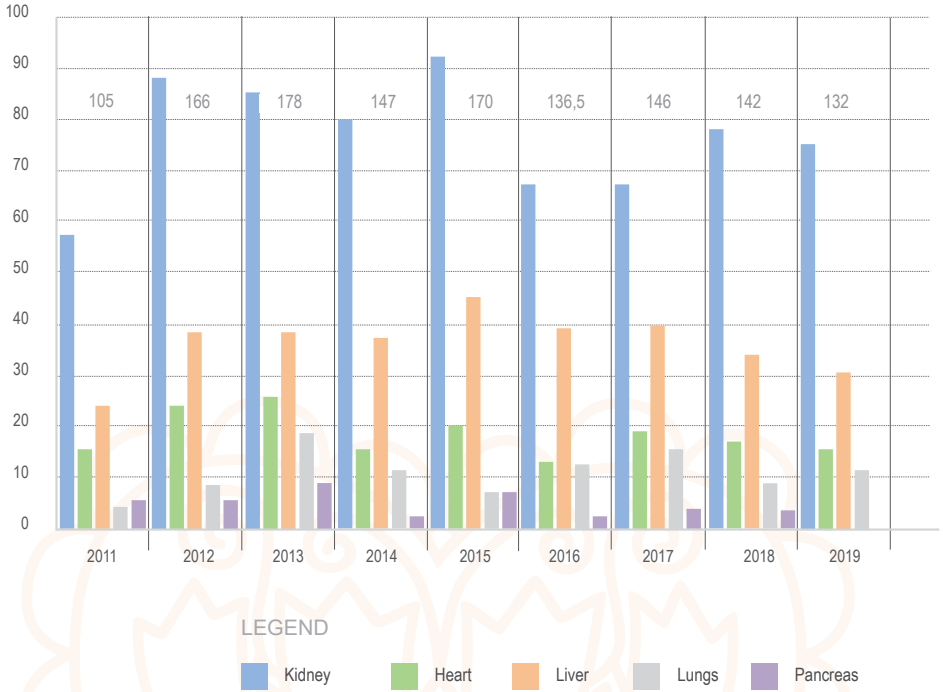
Year	Kidney	Heart	Liver	Lungs (both lobes)	Pancreas	TOTAL
2000	43	14	17	4	13	91
2001	44	19	19	7	6	95
2002	66	28	22	11,5	11	138,5
2003	56	15	21	8	15	115
2004	70	12	25	3,5	6	116,5
2005	39	13	16	9	8	85
2006	59	16	21	7,5	6	109,5
2007	46	12	19	7	3	87
2008	71	11	31	9	2	124
2009	65	9	26	4	6	110
2010	80	20	37	13	8	158
2011	58	14	24	4	5	105
2012	89	25	39	8	5	166
2013	86	26	39	19	8	178
2014	80	16	38	11	2	147
2015	92	20	46	6	6	170
2016	68	13	39	13,5	2	135,5
2017	68	19	40	15	4	146
2018	79	17	34	9	3	142
2019	75	15	31	11	/	132
TOTAL	1.334	334	584	180	119	2.551

Procured organs of deceased donors in Slovenia in the 2000–2010 period



Procured organs of deceased donors in Slovenia in the 2011–2019 period

2.551 procured organs of deceased donors in Slovenia in the 2000–2019 period



TRANSPLANTED SOLID ORGANS

There is one transplantation centre in Slovenia – the Ljubljana University Medical Centre – at which programmes for organ transplantation are carried out. The organ distribution system ensures equal access to medical treatment with organ transplantation for all Slovenian citizens. The tasks of the transplantation centre include:

- preparing recipients for inclusion on the waiting list;
- organ transplantation; and
- treating and guiding patients after transplantation.

Since 2014, the transplantation centre has been managed by the cardiovascular surgeon Dr. Ivan Kneževič, MD.

In 2019, 95 organ transplants were performed. The most transplanted organ is the kidneys and we slightly exceed the average of Eurotransplant countries in terms of the number of all transplants from deceased donors per million people. Considerably higher is the number of transplanted hearts per million people, where in the past few years we have been a world leader.

After relaunching the lung transplant programme in 2018, ten transplantations of both lung lobes were performed in the Ljubljana UMC in 2019. One lung transplantation for a Slovenian paediatric patient was performed in the University Hospital in Vienna (AKH), where the majority of lung transplantations for Slovenian patients were performed till 2018.

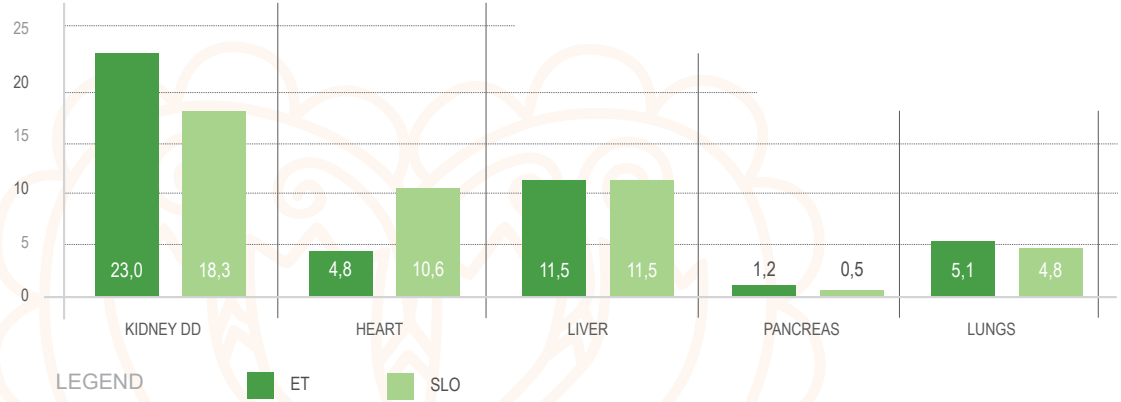
Pediatric transplantations are partly performed in the Ljubljana UMC and partly in nearby European transplantation centres (kidneys in the University Hospital Graz, Austria, and liver in Bergamo, Italy). The relevant departments in the Ljubljana UMC are in charge of treatment and preparation before organ transplantation as well as medical treatment and monitoring of the patient after transplantation.

Transplanted solid organs from deceased donors in the Ljubljana UMC in 2019 and a comparison with Eurotransplant – absolute number and per million people (PMP)

	Kidney DD		Heart		Liver		Pancreas		Lungs		TOTAL	
	No.	PMP	No.	PMP	No.	PMP	No.	PMP	No.	PMP	No.	PMP
SLO	38	18,3	22	10,6	24	11,5	1	0,5	10	4,8	95	44,7
ET	3.191	23,0	668	4,8	1.571	11,5	156	1,2	1.375	5,1	6.961	44,1

Source: http://statistics.eurotransplant.org/

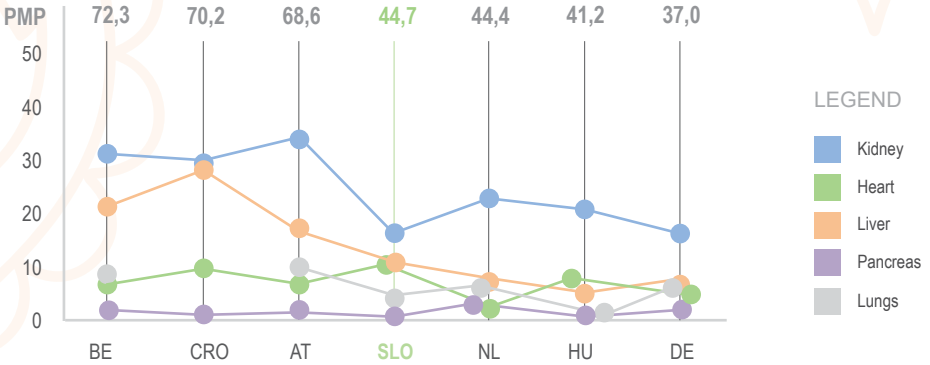
Transplanted solid organs from deceased donors in the Ljubljana UMC in 2019 and a comparison with Eurotransplant



Number of transplanted solid organs from deceased donors per million people (PMP) in Slovenia in 2019 and a comparison with the Eurotransplant countries

ET country	Kidney	Liver	Heart	Pancreas	Lung	Number of transplantations/ PMP in 2019
1. Belgija (BE)	33,9	22,8	7,3	1,8	9,9	72,3
2. Croatia (CRO)	31,4	30,2	9,3	1,2		70,2
3. Avstria (AT)	34,8	15,7	7,6	1,7	11,2	68,6
4. Slovenia (SLO)	18,3	11,5	10,6	0,5	4,8	44,7
5. Netherlands (NL)	26,0	9,7	2,2	1,7	6,1	44,4
6. Hungary (HU)	24,1	8,1	7,4	0,5	1,8	41,2
7. Germany (DE)	19,4	9,3	4,1	1,1	4,3	37,0

Source: http://statistics.eurotransplant.org/



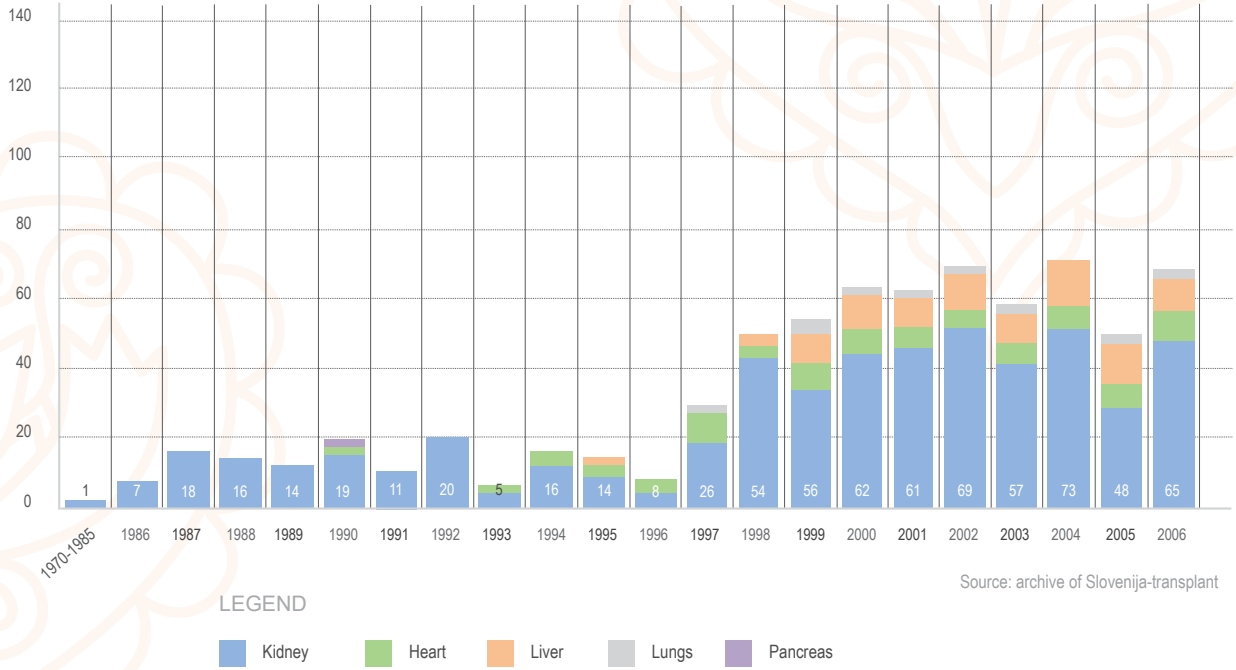
Number of transplanted solid organs of deceased donors in Slovenia in the 1970–2019 period

Source: archive of Slovenija-transplant

Year	Kidney	Heart	Liver	Lungs*	Pancreas	TOTAL
Od 1970 do 1985	1					1
1986	7					7
1987	18					18
1988	16					16
1989	14					14
1990	17	1			1	19
1991	11					11
1992	20					20
1993	4	1				5
1994	14	2				16
1995	10	3	1			14
1996	6	2				8
1997	19	6		1		26
1998	46	4	4			54
1999	37	7	9	3		56
2000	44	7	10	1		62
2001	47	4	9	1		61
2002	55	3	11			69
2003	43	3	9	2		57
2004	55	3	15			73
2005	28	5	13	2		48
2006	48	8**	8	2		66
2007	30	11	10	1		52
2008	52	6	22	4		84
2009	43	18	18	2	2	83
2010	61	19	23	3	1	107
2011	46	14	20	7	1	88
2012	62	29***	27	2		120
2013	60	30	21	8	4	123
2014	55	33	31	3		122
2015	64	24	24	7	5	124
2016	44****	31	27	10	5	117
2017	46****	24	23	8		101
2018	54****	23	27	7	3	114
2019	38	22	24	11	1	96
TOTAL	1.215	343	386	85	23	2.052

* All lung transplants for Slovenian patients were performed in AKH Vienna with the exception of 2003 (1 transplant performed in Ljubljana UMC) and 2018 (2 transplants performed in Ljubljana UMC). In 2019, ten transplantations of both lung lobes were performed in the Ljubljana UMC and one paediatric lung transplantation in the University Hospital in Vienna (AKH).** One heart from a Slovenian donor was transplanted to a Slovenian patient in Graz. *** One heart was transplanted, together with lungs, to a Slovenian patient in Vienna. **** In 2016, 2017 and 2018, two kidneys from a living donor were transplanted. The total number of transplanted kidneys in 2016 is therefore 46, in 2017 48 and in 2018 56.

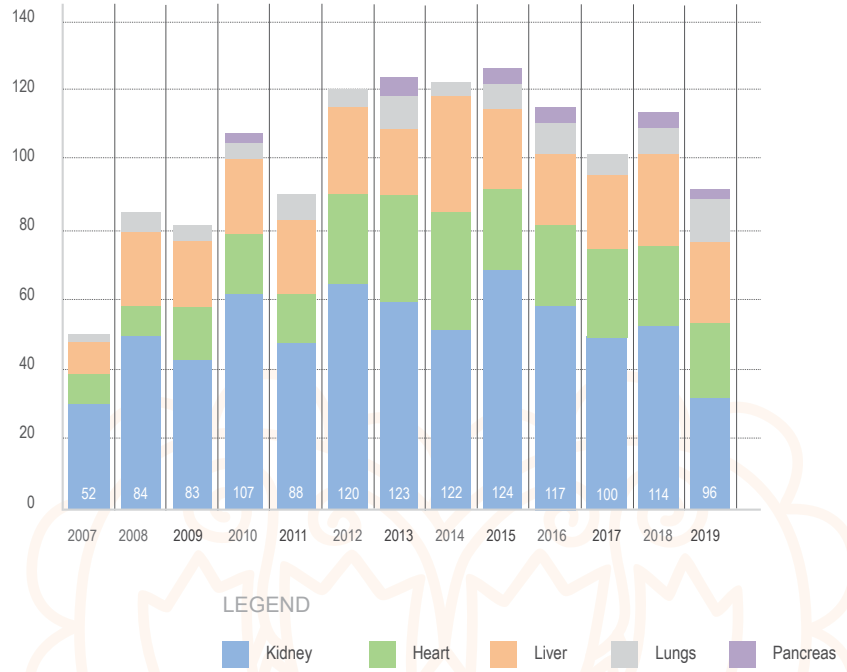
Number of transplanted solid organs of deceased donors in Slovenia in the 1970–2006 period



Source: archive of Slovenija-transplant

Number of transplanted solid organs of deceased donors in Slovenia in the 2007–2019 period

2.052 transplanted solid organs of deceased donors in SLO in the 1970–2019 period



Source: archive of Slovenija-transplant

THE SUCCESSFULNESS OF SLOVENIAN ORGAN TRANSPLANT PROGRAMMES

Patient survival after a heart transplant

From 1990 to the end of 2019, the Ljubljana UMC performed 343 heart transplants and another 22 in 2019. Eighteen (82 %) patients had an urgent and 4 (18 %) a regular transplant. According to Eurotransplant data, the Ljubljana UMC was again ranked in the top 10 (out of 42) largest heart transplant centres in the Eurotransplant area and may be compared by number of transplantations with the biggest centres in Germany, Belgium, Hungary and Austria.

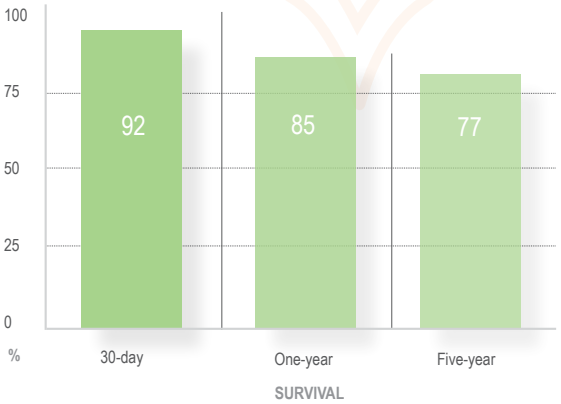
The multi-year average (2009–2018) waiting period for an elective heart transplant was about 248 days (median: 67 days) and for an urgent heart transplant about 50 days (median: 50 days). In 2019, the average waiting period for an elective heart transplant was 452 days (median: 238 days) and for an urgent heart transplant 59 days (median: 50 days).

The patient survival rates are comparable with those from the international reference register kept by the *International Society for Heart and Lung Transplantation* (ISHLT).

Survival of adult heart transplant recipients in % (1990–2018, n = 321)

30-day survival	One-year survival	Five-year survival
92 %	85 %	77 %

Source: Report on implementation of the programme for advanced heart failure and heart transplantation for 2018 (Cardiology Department, Ljubljana University Medical Centre)



Patient survival after a kidney transplant

In the period in which Slovenija-transplant has been a member of Eurotransplant (1 January 2000 - 31 December 2019), 983 kidneys of living and deceased donors have been transplanted. In the first post-transplantation year the clinical, biopsy-proven acute rejection of the transplant was reported in 12.7% of all patients.

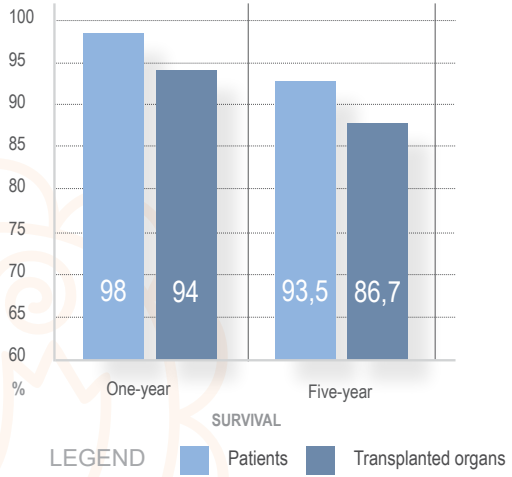
Some recipients had a transplanted kidney in combination with other organs (pancreas, liver, heart).

In the 2013–2016 period, the median time until transplantation was 300 days. Based on Eurotransplant data for the 3-year period (2010–2014), 55 % of patients were given a kidney transplant within the first year of being included on the waiting list, whereas after three years the respective figure is 80 %.

According to Eurotransplant data for the 2000 −2014 period, the current 1-year and 5-year survival of Slovenian patients and grafts is above the Eurotransplant members' average and comparable with the most developed centres around the world.

Survival of kidney transplant recipients and transplanted organs in % (2000−2019, n = 983)

One-year survival	Five-year survival
Patients	
98 %	93,5 %
Transplanted organs	
94%	86,7 %



Source: Quality indicators of the Kidney Transplantation Centre (Department of Nephrology, University Medical Centre Ljubljana)

Patient survival after a liver transplant

Between 1995 and 2019, the University Medical Centre Ljubljana carried out 386 liver transplants. Of all patients with a liver transplant, 63 % needed the procedure due to cirrhosis of the liver, 10 % acute liver failure, 9.7 % liver cancer, 9.1 % cholestatic/congenital diseases, and 2.1 % due to metabolic liver disease. Other reasons for the transplant (5.9 %) include benign liver tumour or polycystic liver disease and Budd-Chiari syndrome.

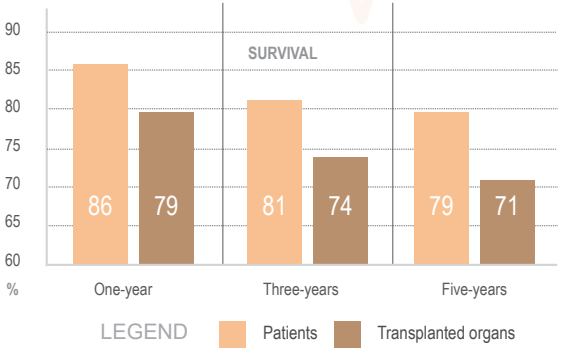
The average waiting period for a liver transplant in 2019 was about 254 days (median: 115 days).

Survival of liver transplant recipients and transplanted organs in % (1988–2018, n = 291 (patients) and n = 323 (transplanted organs))*

One-year survival	Three-year survival	Five-year survival
Patients		
86 %	81 %	79 %
Transplanted organs		
79 %	74 %	71 %

Source: ELTR (European Liver Transplant Registry, SLLUBL: Specific Analyses December 2018)

* Data for 2019 will be available in mid 2020; published here are data for 2018



Source: Clinical Department of Gastroenterology, University Medical Centre Ljubljana

Patient survival after a pancreas transplant (in combination with kidney)

In the period from February 2009 to 31 December 2019, 22 pancreas transplants were carried out, all concurrently with kidney. In 2019, one combined pancreas and kidney transplantation was performed.

After one year, 17 pancreases were functioning, whereas 5 were removed in the early post-transplant period.

The 1-year survival of a pancreas graft was 77.8 % (n=18) and the 3-year survival was also 77.8 % (n=18). The 1-year and 3-year survival of a kidney graft in patients with a combined pancreas-kidney transplant was 94.4 %.

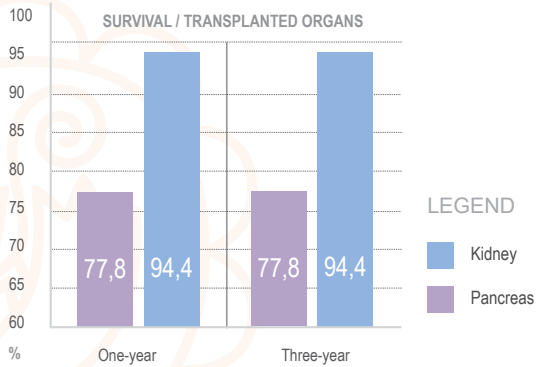
One year, 3 years and 5 years after transplant all pancreas-transplant recipients were alive, leading to a 1-year, 3-year and 5-year survival rate of 100 %.

All patients whose pancreas was functioning after 1 year also had a functioning pancreas on 31 December 2019, meaning they were insulin-independent. One patient died 6 years after the transplant due to a cardiogenic shock; his pancreas and kidney were still functioning.

Survival of combined pancreas-kidney transplant recipients and transplanted organs in % (1988–2019, n=22 (patients) in n=18 (transplanted organs))

One-year survival		Three-year survival	
Patients			
100 %		100 %	
Transplanted organs			
Pancreas	Kidney	Pancreas	Kidney
77,8 %	94,4 %	77,8 %	94,4 %

Source: Associate Professor Dr. Damjan Kovač, DMS (Department of Nephrology, UMC Ljubljana)



Patient survival after a lung transplant

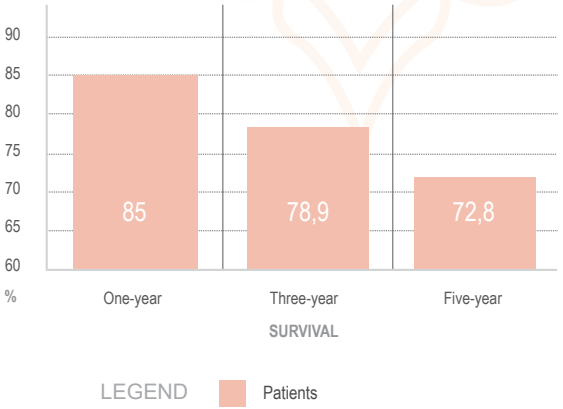
In the 1997–2019 period, 85 lung transplants were performed on Slovenian patients, one of whom had to undergo a re-transplant. After relaunching the lung transplant programme in 2018, ten transplantations of both lung lobes were performed in the Ljubljana UMC in 2019. The first transplantation of one lung lobe was performed in the Ljubljana UMC in 2003.

In 2019, a total of 11 lung transplantations was performed on Slovenian patients, with one of them being a paediatric transplantation that was performed in the University Hospital in Vienna.

Survival of lung transplant recipients in % (1997–2019, n=85)

One-year survival	Three-year survival	Five-year survival
Patients		
85 %	78,9 %	72,8 %

Source: doc. dr. Matevž Harlander, MD (Department of Pulmology and Alergology, University Medical Centre Ljubljana)



Tissues and cells

TRANSPLANTATION OF HAEMATOPOIETIC STEM CELLS

The transplantation of haematopoietic stem cells (HSCs) is the dominant type of cell treatment since over 70 malignant and non-malignant diseases can be treated in this way, whereas for specific haematological diseases this is the main and only therapeutic possibility a patient's recovery. The modern method of medical treatment using HSCs is more than 90% successful in optimal conditions *(http://www.ztm.si)*. For such success, good donor-recipient immunological (HLA) matching is required. The HLA system differs in every person and it is very demanding to find a suitable match. In the international community, doctors decided to establish large registers of typified volunteer donors of HSCs to improve the possibility of HLA matching and thus also the outcomes of transplants. All data are appropriately protected against unauthorised use.

There are several types of donor-recipient matching. If it is possible to use a patient's own HSCs, this is called an autologous donation. When this proves impossible, we look for another donor who may or may not be related to the recipient. Donation by another donor is called allogeneic and a donor is sought both in Slovenia and abroad.

The Slovenija-donor register

In Slovenia a register of non-related donors, Slovenia Donor, was established in 1991 and the following year it became a full member of the world register *Bone Marrow Donors Worldwide* (BMDW).

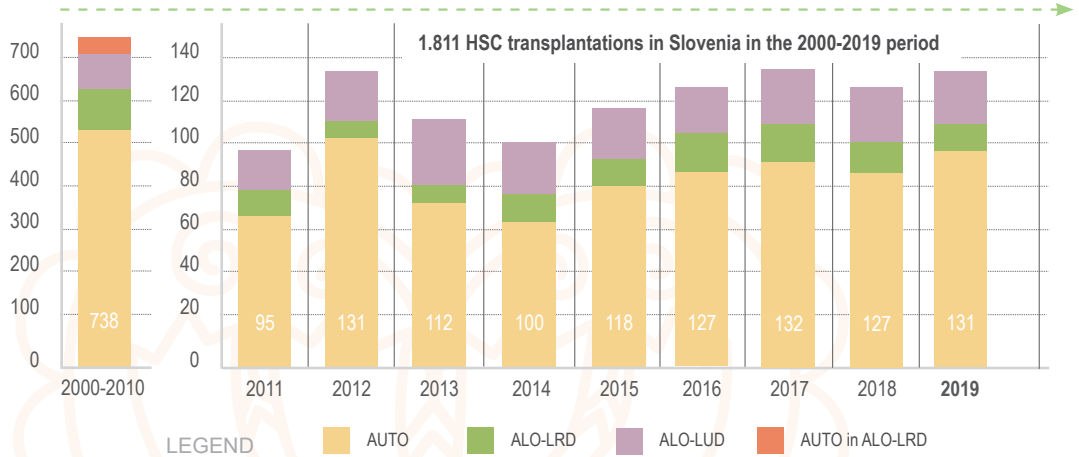
On 31.12.2019, the Slovenia Donor register featured 20.597 people, of whom 19.475 were entered in the BMDW world register.

HSC transplantations in Slovenia in the 2000–2019 period

Transplantion type	2000-2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
AUTO	531	68	101	74	63	84	86	92	88	89
ALO-LRD	102	9	8	7	11	10	15	12	13	11
ALO-LUD	84	18	22	31	26	24	26	28	26	31
AUTO and ALO-LRD	21									
TOTAL	738	95	131	112	100	118	127	132	127	131

AUTO – autologous transplantations, **ALO** – allogeneic transplantations, **LRD** – living related donor, **LUD** – living unrelated donor

Source: Yearly report of ZTM – Slovenija donor, data collected monthly for Slovenija-transplant archives



CORNEA PROCUREMENT AND TRANSPLANTATION PROGRAMME

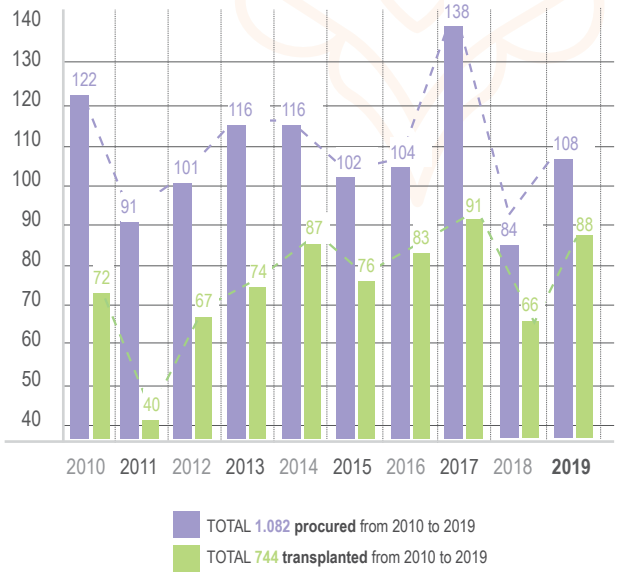
Cornea transplantation is one of the most frequent and most successful tissue transplantations in the world. This medical treatment is often the only method that can improve sight after a disease or injury. In Slovenia, corneas are procured from deceased donors after a cardiac arrest or proven brain death. The removal of corneas is possible following consent given by the deceased person

Procured and transplanted corneas in the 2010–2019 period

Source: archive of Slovenija-transplant

Year	No. of procured corneas	*No. of transplanted corneas
2010	122	72
2011	91	40
2012	101	67
2013	116	74
2014	116	87
2015	102	76
2016	104	83
2017	138	91
2018	84	66
2019	108	88

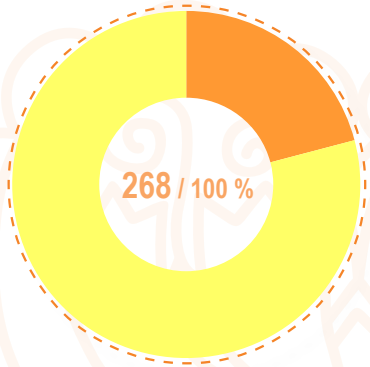
* 2010-2017 – cornea transplants performed in Ljubljana UMC only; from 2018 on, cornea transplants performed in Ljubljana UMC and Maribor UMC



before their death or if their close relatives do not object. The final decision on the suitability of corneas for transplantation is always taken by the recipient's responsible doctor. Corneas are transplanted in two transplantation centres: the Department of Ophthalmology in the Ljubljana UMC and the Department of Ophthalmology in the Maribor UMC.

Waiting list of patients seeking a cornea transplant at the Department of Ophthalmology in the Ljubljana UMC (on 1 April 2020, as a percentage)

Diagnosis	Number of patients
Keratoconus	56
Other diagnoses	212
TOTAL	268



LEGEND

- Diagnosis of keratoconus: **56 patients (21 %)**
- Other diagnoses: **212 patients (79 %)** (injuries, degeneration, retransplantation, corneal macula, Fuchs dystrophy, endothelial dystrophy, cornea guttata, aphakia and pseudophakia, bullous keratopathy, infections, other)

Source: archive of Slovenija-transplant

OTHER TISSUES AND CELLS

Traceability and transparency in transplant programmes or tissue and cell use programmes for treatment purposes

Slovenija-transplant has established co-operation with all tissue and cell institutions, which must hold a valid permit from the Agency for Medicinal Products and Medical Devices of the Republic of Slovenia (hereinafter: JAZMP). We ensure traceability and transparency by promptly collecting and reviewing reports written by the institutions for tissues and cells which present the donation, procurement, processing, storing, allocation, use and disposal of tissues and cells.

At the end of the year, Slovenija-transplant compiles an aggregate annual report based on annual reports issued by individual tissue and cell institutions. We also compile an annual final report on serious adverse events and reactions and submit it to the JAZMP, which then reports thereon to the European Commission.

Tissue and cell institutions along with quality and safety assurance

In Slovenia, 26 institutions are involved in the activity of procuring tissues and cells at the national level. Fifteen hospitals are included in the programme and, within these, 40 clinical departments. In terms of their status, 18 tissue and cell institutions are public and 8 privately owned. Private institutions hold a permit exclusively for the autologous procurement of tissues and cells.

Slovenija-transplant and the JAZMP ensure that the system functions and promptly identify and discuss any deviations that could affect the quality and safety of the tissues and cells of donors, recipients as well as the staff involved in the processes.

To obtain a permit, every institution must comply with strict expert and legal terms and provisions. All institutions have set up a quality assurance system where all the procedures for ensuring con-

ditions for tissue and cell quality and recipient safety are defined. They are regularly supervised by the JAZMP, whereas Slovenija-transplant also performs verification of the reported data.

Artificial insemination with biomedical assistance and reproductive cells

Four centres are registered in Slovenia for the activity of artificial insemination with biomedical assistance for couples incapable of conception to produce a child, namely the Ljubljana AIBA Centre, the Maribor AIBA Centre, the Postojna AIBA Centre and the Dravlje Health Centre.
The scope of their activities is evident from the table showing the procured and used tissues and cells. This is the most comprehensive area in terms of the number of procedures conducted.

In 2019, the Ministry of Health of the Republic of Slovenia formed an expert group, composed of the AIBA centres from Ljubljana, Maribor and Postojna, the Zdravje Private Health Institute and Slovenija-transplant. This group is drawing up expert guidelines and legislation for the establishment of a national AIBA register to which individual AIBA centres are to report their activities by certain deadlines. The register is to be managed by the National Institute of Public Health (NIJZ) on whose premises it will be physically installed. Slovenija-transplant will have access to the data for the purpose of ensuring the traceability, transparency as well as the quality and safety of tissues and cells.

Procuring and storing umbilical cord blood and the umbilical cord

In Slovenia we also procure haematopoietic stem cells from umbilical cord blood and the umbilical cord as well as other tissues (e.g. milk teeth). One public tissue bank, i.e. the Blood Transfusion Centre of Slovenia (hereinafter: BTCS), and three privately-owned institutions (Izvorna celica, Biobanka and FH-S) hold a permit for this activity. The public umbilical cord blood bank within the BTCS has stopped accepting samples of umbilical cord blood because a sufficient number of samples had been collected and stored to cater to the needs of Slovenia.

Number of procured tissues and cells in the 2009–2019 period

Year	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Skin*	28	45	22	36	85	89	52	57	32	22	24
Bones*	38	123	108	67	93	82	147	74	80	78	71
Soft bone grafts*	22	39	/	3	11	3	9	/	12	/	/
Cartilage*	37	21	4	12	11	11	12	/	/	/	/
Reproductive cells (no. of cells)	15.854	43.472	8.640	27.479	41.929	37.542	39.769	26.191	36.338	13.778	26.813

*Unit: number of samples taken

Number of tissues and cells used in the 2009–2019 period

Year	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Skin*	36	10	14	34	67	23	31	28	/	20	3
Bones*	23	47	57	97	59	62	92	82	72	71	81
Soft bone grafts*	12	/	2	2	3	4	3	5	2	3	5
Cartilage*	15	/	3	7	4	9	5	1	/	/	1
Reproductive cells	1.450	2.018	29.651	23.330	23.506	27.271	31.127	26.620	31.817	12.110	5.109

*Unit: number of samples used

Source: archive of Slovenija-transplant

Number of procured umbilical cord blood units

Institution / Year	2015	2016	2017	2018	2019
Izvorna celica	76	144	107	82	81
Biobanka	175	178	266	110	224
FH-S	8	45	101	169	192
Neocelica	238	0*	0*	0*	0*

*this institution stopped operating

Number of procured umbilical cord units

Institution / Year	2015	2016	2017	2018	2019
Izvorna celica	60	116	96	52	73
Biobanka	32	150	222	96	212
FH-S	8	42	96	114	196
Neocelica	198	0*	0*	0*	0*

*this institution stopped operating

Source: archive of Slovenija-transplant

ADVERSE EVENTS AND REACTIONS

Slovenija-transplant is responsible for monitoring adverse events and reactions as well as deviations in the area of the procurement of tissues and cells for transplantation and/or tissue vigilance. The aim of collecting reports on adverse events and reactions or even raising doubts about them is to assure the quality of procedures and thus prevent the damage or even loss of tissues and cells.

Reporting takes place using prescribed forms, whereby initial and final reports must be submitted for each case. Both forms are attached to the Rules on Tissue Vigilance. Reporting entails several phases: identification of deviation, detailed description, adoption of appropriate measures for preventing damage to tissues and cells as well as people, reporting to relevant institutions and notification of all tissue and cell institutions which were provided with tissues and cells in which deviations were identified.

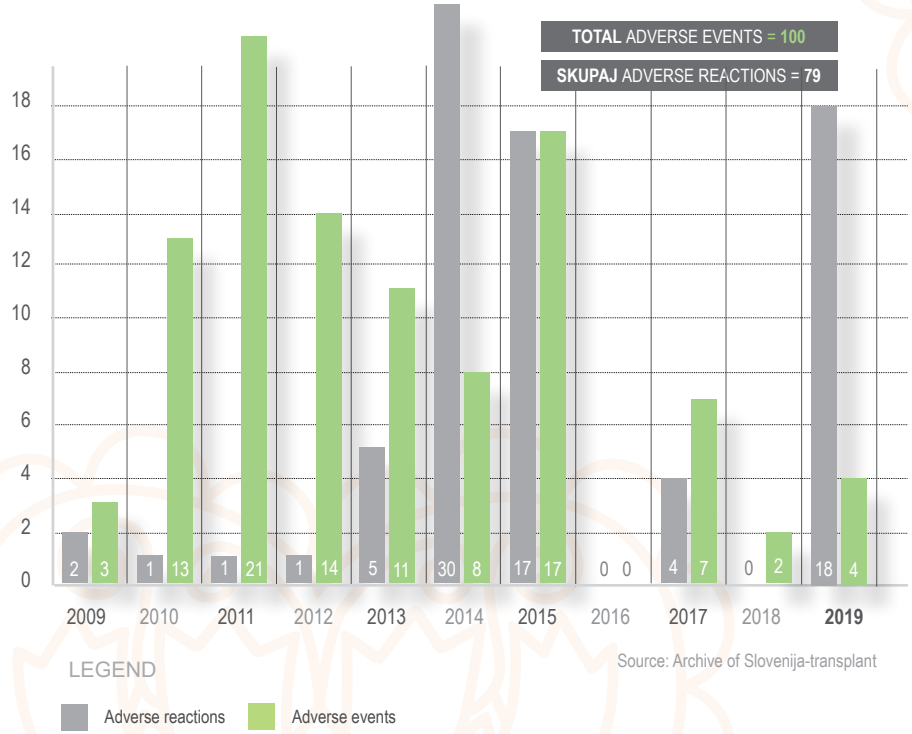
All data collected in the tissue vigilance system are anonymised so as to ensure privacy and, on the other hand, comply with the so-called no-blame culture, which means encouraging reporting along with searching for solutions and improvements, while not judging and punishing implementers on a personal level.

In 2019, Slovenija-transplant received four reports on adverse events – all occurring in the tissue and cell procurement chain. Two cases were detected in an AIBA centre and two in bone procurement. We prepared an analysis and applied corrective measures. There were no serious consequences in any of the four cases and the risk of reoccurrence was assessed to be low.

An AIBA centre also dealt with 18 cases of adverse reactions. Six cases involved ovarian hyperstimulation syndrome and six patients were hospitalised. In 12 cases, strong venous bleeding occurred, but hospitalisation was not required.

We found that, in order to improve overall awareness, it is necessary to organise additional training on tissue vigilance and adverse event reporting because it is possible that the reporting of data on vigilance cases is slightly underrated.

Number of adverse events and reactions in the 2009–2019 period



PUBLICATIONS AND ORAL PRESENTATIONS

Original and review scientific articles

- Berzelak, N., Avsec, D., Kamin, T. (2019). Reluctance and willingness for organ donation after death among the Slovene general population. Slovenian journal of public health, 58(4): 155–163. Available at: https://content.sciendo.com/view/journals/sjph/58/4/article-p155.xml.
- Lušicky, P., Avsec, D. (2019). The role of the Institute of the Republic of Slovenia for the transplantation of organs and tissues Slovenija-transplant in the donor programme. Slovenian Medical Journal, 88(1–2): 3–20.
  Available at: https://vestnik.szd.si/index.php/ZdravVest/article/view/2833. (in slo language)
- Avsec, D. (2019). Organ and tissue donation and retrieval. In Kremžar, B., Voga, G., Grosek, Š. (eds.), Intensive care medicine - handbook. Ljubljana: Slovenian society for intensive care medicine. p. 991–997. (in slo language)

Professional articles

- Avsec, D. (2019). Legislative and ethical aspects of transplant medicine in Slovenia. In Buturović-Ponikvar, J. (ed.), Ethical challenges in organ transplantation. Ljubljana: UMC Ljubljana, p. 45–53.
- Gadžijev, A. (2019). New trends in transplant medicine. In Buturović-Ponikvar, J. (ed.), Ethical challenges in organ transplantation. Ljubljana: UMC Ljubljana, p. 71–74.
- Uštar, B. (2019). Donor and transplantation activity in 2018. Transplant: Journal of Slovenian patient association, June 2019: 4–8. (in slo language)
- Uštar, B. (2019). Statistical data in 2019. Transplant: Journal of Slovenian patient association, December 2019: 4. (in slo language)

- Šimenc, J., Avsec, D. (2019). First year of electronic registration for post-mortem organ donation. Transplant: Journal of Slovenian patient association, December 2019: 5-7. (in slo language)
- Šimenc, J., Avsec, D. (2019). Give life a chance. Kidney: Journal of Slovenian kidney patient association, December (3): 5–6. (in slo language)
- Uštar, B. (avtor, ur.), Šimenc, J., Gadžijev, A., Čebulc, G., Jakovac, J., Avsec, D. (eds.). (2019). Give life a chance: Donor and transplantation activity in Slovenia in 2018. Ljubljana: Institute for transplantation of organs and tissues of the Republic of Slovenia. Available at: http://www.slovenija-transplant.si/uploads/media/TRANSPLANT_BROSURA__2018_SLO_EN.pdf.
- Organ and tissue donation. In Sotler, R. (ed.). Basics of first aid. Handbook for motor cyclers. Ljubljana: Red cross Slovenia, p. 198–199. (in slo language)

Lectures and conferences (in chronological order)

- Šimenc, J.: The role of (new) media in raising social awareness in organ and tissue donation. Eudonorgan – Social awareness event, Budapest (Hungary), 14. 1. 2019.
- Šimenc, J., Avsec, D.: Creating good reputation on Facebook: the case of Slovenia-transplant. 5th ELPAT congress Developing dialogue, pioneering practice, Krakow (Poland), 26.–29. 4. 2019.
- Avsec, D.: Obstacles in transplant medicine in the ICU. 28. International symposium of intensive care medicine, Bled (Slovenia), 31. 5.–1. 6. 2019.
- Gadžijev, A.: New trends in transplant medicine. 28. International symposium of intensive care medicine, Bled (Slovenia), 31. 5.–1. 6. 2019.

- Šimenc, J.: Social media as a tool to inform publics on organ donation. 28. International symposium of intensive care medicine, Bled (Slovenia), 31. 5.–1. 6. 2019.
- Avsec, D.: Legislative and ethical aspects of transplant medicine in Slovenia. Ethical challenges in organ transplantation, UMC Ljubljana, Ljubljana (Slovenia), 7. 6. 2019.
- Gadžijev, A.: New trends in transplantation medicine: donation after circulatory death. Ethical challenges in organ transplantation, UMC Ljubljana, Ljubljana (Slovenia), 7. 6. 2019.
- Uštar, B., Avsec, D.: Introducing E-registration in Slovene donor registry. 19th ESOT congress Inspiring minds, driving progress, Copenhagen (Denmark), 15.–19. 9. 2019.
- Avsec, D. & Kušar, B.: Slovenija-transplant – case presentation. Microcop IT conference, Brdo pri Kranju (Slovenia), 15. 10. 2019.
- Šimenc, J. & Avsec, D.: Medical anthropology in practice: the case of Slovenija-transplant (invited lecture). Health and society: Interdisciplinary research of health, disease and healing. Faculty of arts, University of Ljubljana, Ljubljana (Slovenia), 24. 10. 2019.
- Avsec, D.: General aspects of organ donation and transplantation; Communication in the ICU and Declaration of Death; Public Education on Organ Donation 3rd International Training Course in Transplant Coordination, Istanbul (Turkey), 25.–29. 11. 2019.
- Šimenc, J.: Using digital media tools for donation professionals. 3rd International Training Course in Transplant Coordination, Istanbul (Turkey), 25.–29. 11. 2019.
- Avsec, D.: Social significance of organ donation (invited lecture). China International Organ Donation Conference, Kunming (China), 7. 12. 2019.

LITERATURE

- Website of Slovenija-transplant: http://www.slovenija-transplant.si/.
- Website of the Blood Transfusion Centre of Slovenia: http://www.ztm.si/register-darovalcev/slovenija-donor/.
- Act Regulating the Obtaining and Transplantation of Human Body Parts for the Purposes of Medical Treatment (ZPPDČT), Official Gazette of the RS, no. 56/2015
- Council of Europe Convention against Trafficking in Human Organs (CM, 9.7.2014)
- Website of Eurotransplant: http://www.eurotransplant.org/cms/.
- Website of the European Directorate for the Quality of Medicines & HealthCare (EDQM): https://www.edqm.eu/.
- Guide to the Quality and Safety of Organs for Transplantation. European Committee (Partial Agreement) on Organ Transplantation (CD-P-TO), European Directorate for the Quality of Medicines & Health Care, Strasbourg; 7th ed. 2018.
- Guide to the Quality and Safety of Tissues and Cells for human application. European Committee (Partial Agreement) on Organ Transplantation (CD-P-TO), European Directorate for the Quality of Medicines & Health Care, Strasbourg; 4th ed. 2019.
- The Madrid Resolution on Organ Donation and Transplantation: https://www.edqm.eu/sites/default/files/article_the_madrid_resolution_on_organ_donation_and_transplantation_transplantation_journal_june_2011.pdf
- Razvoj transplantacijske medicine v Sloveniji: programi, smernice in perspektive. Editors: Danica Avsec and Zvonka Zupanič Slavec; illustrations: Radko Oketič. Ljubljana: Institute for Transplantation of Organs and Tissues of the Republic of Slovenija Slovenija-transplant; Celje: Celjska Mohorjeva družba: Društvo Mohorjeva družba, 2016.
- Donorski program: Postopki za izvajanje v donorskih bolnišnicah. Authors: Andrej Gadžijev, Danica Avsec. Ljubljana: Zavod RS za presaditve organov in tkiv Slovenija-transplant. Ljubljana, 2018.
- Preliminary numbers 2019, IRODaT (International Registry in Organ Donation and Transplantation), www.irodat.org.
- Website of EUDONORGAN project: http://eudonorgan.eu/.
- Buturović-Ponikvar, J (ed.), Zbornik predavanj strokovnega simpozija Etični izzivi pri transplantaciji organov. Ljubljana: Univerzitetni klinični center Ljubljana.

slovenija
transplant

Zavod RS za presaditve organov in tkiv
Slovenija-transplant
Institute for Transplantation of Organs and Tissues of the Republic of Slovenia
Zaloška 7, 1000 Ljubljana, Slovenija

Spletna stran/*web page:* www.slovenija-transplant.si
e-pošta/*e-mail:* info@slovenija-transplant.si
Telefon: + 386 1 300 68 60
Faks: + 386 1 300 68 66

Direktorica/*Director*
Prim. Danica Avsec, dr. med., svetnica
GSM: + 386 41 760 917
E-pošta/*e-mail:* danica.avsec@slovenija-transplant.si