

NEW HEART: Yusra Gadban watches over her daughter, Samah, 12, who received a heart transplant at Schneider Hospital in Petah Tikva in 2005

The Donation Dilemma

Ina Friedman

THREE YEARS AGO, Moshiko Sharon, now 13, of Moshav Hodaya near Ashkelon, was arguably an Israeli icon. Having suffered from debilitating kidney disease from birth, he had just undergone his second kidney transplant, after his body showed signs of rejecting the organ implanted in it two years earlier. The first kidney came from an Israeli who had been declared brain dead following an accident. The second came from the most unexpected of live donors: Eric Swim, then 38, a practicing Christian from the rural town of Marysville, Kansas, who had developed a deep interest in Judaism and discovered Moshiko's plight while surfing the Web and reaching the site of the Halachic Organ Donor Society (HOD).

"I was deeply touched by the article on Moshiko posted there, and it got me to thinking: 'What if he were my child?'" says Swim in a phone interview with *The Report*. "So after thoroughly discussing the matter with my family, I decided to step forward and see what I could do." His first move was to contact Robert Berman, the founder and director

As the Knesset crafts a law governing organ transplants, a debate is raging over how to raise the donation rate, by offering donors compensation, without trampling on ethics

of HOD, who put him in contact with the Sharon family. After receiving positive results from the tests to determine the compatibility of his kidney, Swim flew to Israel and underwent two stringent psychological tests required by the Health Ministry, received the ministry's approval, and finally checked into the Rabin Medical Center to donate the kidney that Moshiko carries today.

Moshiko, who has developed a close relationship with Swim's family and speaks of him as "my brother," is loath to discuss his past tribulations and describes himself as "just a normal kid who goes to school and comes home to sit at my computer or play with friends." But his mother, Rahel, 55, still has vivid memories of the "bad years," when she had to devote herself totally to caring for him. "I had to administer injections and the daily dialysis he underwent at home," she recalls. "And our home life was destroyed: My five older children didn't know what it meant to have a mother, and we had to send two of them to boarding

schools. It was unspeakably difficult." Little wonder that she literally glows when she speaks of Swim and his act of altruism. "Our gratitude to him knows no bounds."

In contrast, and by sheer coincidence, two doors down the road, Shiran Azrak, 19, is contending with the total disruption of her life. Tests done last fall revealed that her kidneys were operating at only 10 percent capacity, requiring her to undergo dialysis three times a week at a nearby hospital. She was placed on the national waiting list for a kidney transplant. But because more than 500 others preceded her on that list, and her wait for a compatible donor could have gone on for years, her family signed on with one of the private Israeli companies (whose name they preferred not to disclose) that arrange transplants abroad. Through loans and donations, the Azraks then raised \$82,000 for Shiran to undergo transplant surgery in Colombia, South America. (The cost of a transplant carried out in Israel is covered by the National Health Insurance

Law, but Israeli HMOs pay for such surgery abroad only if a member carries their supplementary medical insurance, which the Azraks do not.)

From there it was all downhill. "The Colombian doctor told us he would not perform a transplant until one of Shiran's kidneys had been removed and she had recovered from the operation," says her mother, Rahel, 47. "All in all, our experience there was traumatic," she confides. "I'm not saying the Israeli company was at fault, but it had just begun working with Colombia, and apparently we were the guinea pigs," she continues. "It kept sending money to the team handling us there and told them to give us everything we need. But the Colombians limited what we could receive, and I had to pay for lots of things out of pocket. Besides, we felt terribly isolated, so far from the support of our family and friends." The operation to remove one of Shiran's kidneys was performed; the company still owes her the transplant of the replacement. For, given their unsatisfactory experience, the Azraks decided to return to Israel, rather than wait for a kidney to materialize in Colombia.

Now Shiran, whose large brown eyes project a deep sadness, is back on dialysis three times a week and speaks candidly of having slipped into a depression. The two women don't want to return to Colombia and say the company is examining possibilities in the Philippines. "What we'd really like is to do the transplant here in Israel, and Shiran is back on the waiting list," says Rahel. "Even if we were to receive an offer from a live donor, as Moshiko did, who will believe that he is willing to do it for free," she frets. "The state is very suspicious about such acts of altruism and would make things very difficult for us all."

UNDER THE BEST OF CIRCUMSTANCES, organ donation is hard to sell in Israel. According to the Health Ministry's National Center for Transplants (NCT), at the end of last year 833 people were on the national list waiting for families to donate the organs of loved ones who have been pronounced brain dead, and 279 transplants were performed. Of the 518 patients waiting for kidneys, which can also come from live donors, only 87 received them.

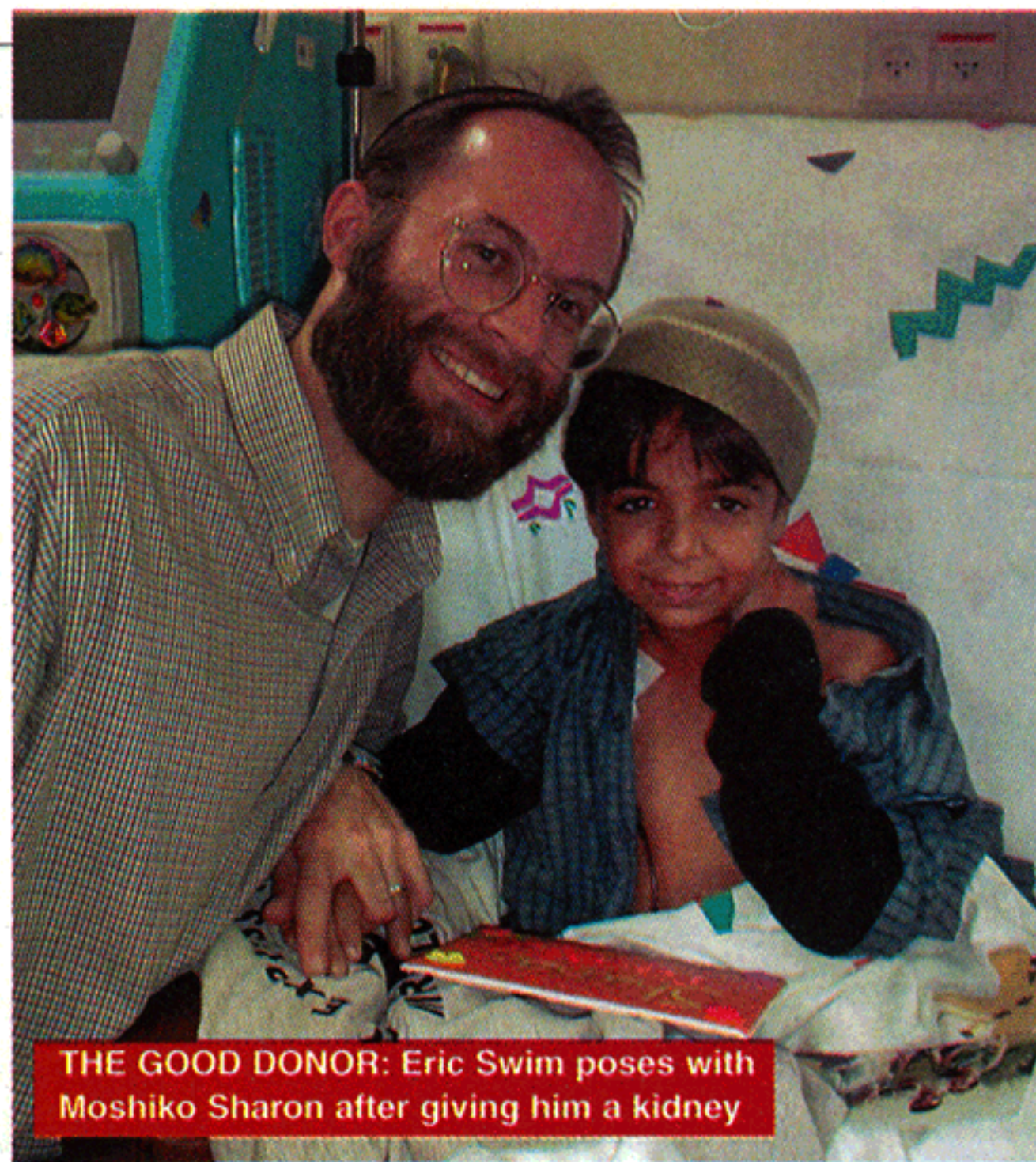
The crux of the problem is the low rate of donations. Just 7.2 percent of Israel's adult population (compared with some 30-35 percent in other Western countries) have signed up for the NCT's donor cards, denoting per-

mission to harvest their organs in the event of brain death. What's more, only 50 percent of the families approached for consent to recover the organs of their loved ones — as required by law, whether or not the patient carries a card — agree to do so.

"The result is many needless deaths," says Berman, who notes that eight organs can be recovered from each donor in this condition. "In 2001, when I started HOD, 130 Israelis were declared brain dead and could have yielded over 1,000 organs, had their families not nixed the idea," he says. "Meanwhile, every year about 100 people die in Israel while waiting for transplants."

The relatively low rate of card holders and approving relatives is widely ascribed to a mixture of cultural factors — particularly the ingrained belief that the halakha (Jewish religious laws) forbids any tampering with the dead — and misconceptions about the meaning of brain death. Over the years, the NCT has mounted campaigns to raise registration for donor cards but with limited success. Tali Pouny, who has been personally promoting registration for these cards since her husband underwent a kidney transplant in Colombia last year (see box on page 19), is not surprised by this situation. "The ignorance of Israelis on the subject of organ donations is appalling," she laments. "Many people I've encountered don't know the difference between brain death and a coma, while others are convinced that if they carry a donor card, doctors will do less to save their lives."

Berman, who established HOD to dispel the belief that recovering organs runs counter to halakha, has repeatedly met laymen who insist that Jewish law categorically forbids mutilating, delaying the burial of, or in any way deriving benefit from the body of the deceased. "I even had a conversation with a man who, while eating a cheeseburger, protested that HOD's principles defy halakhaic tenets," he relates. "I know I don't live a Jewish lifestyle," he told me, "but when it comes to death, I want to be more *frum* [rigorously religious]." Yet HOD has culled the opinions of 187 respected



THE GOOD DONOR: Eric Swim poses with Moshiko Sharon after giving him a kidney

COURTESY ERIC SWIM

Orthodox rabbis that organ donation is fully congruent with the halakha.

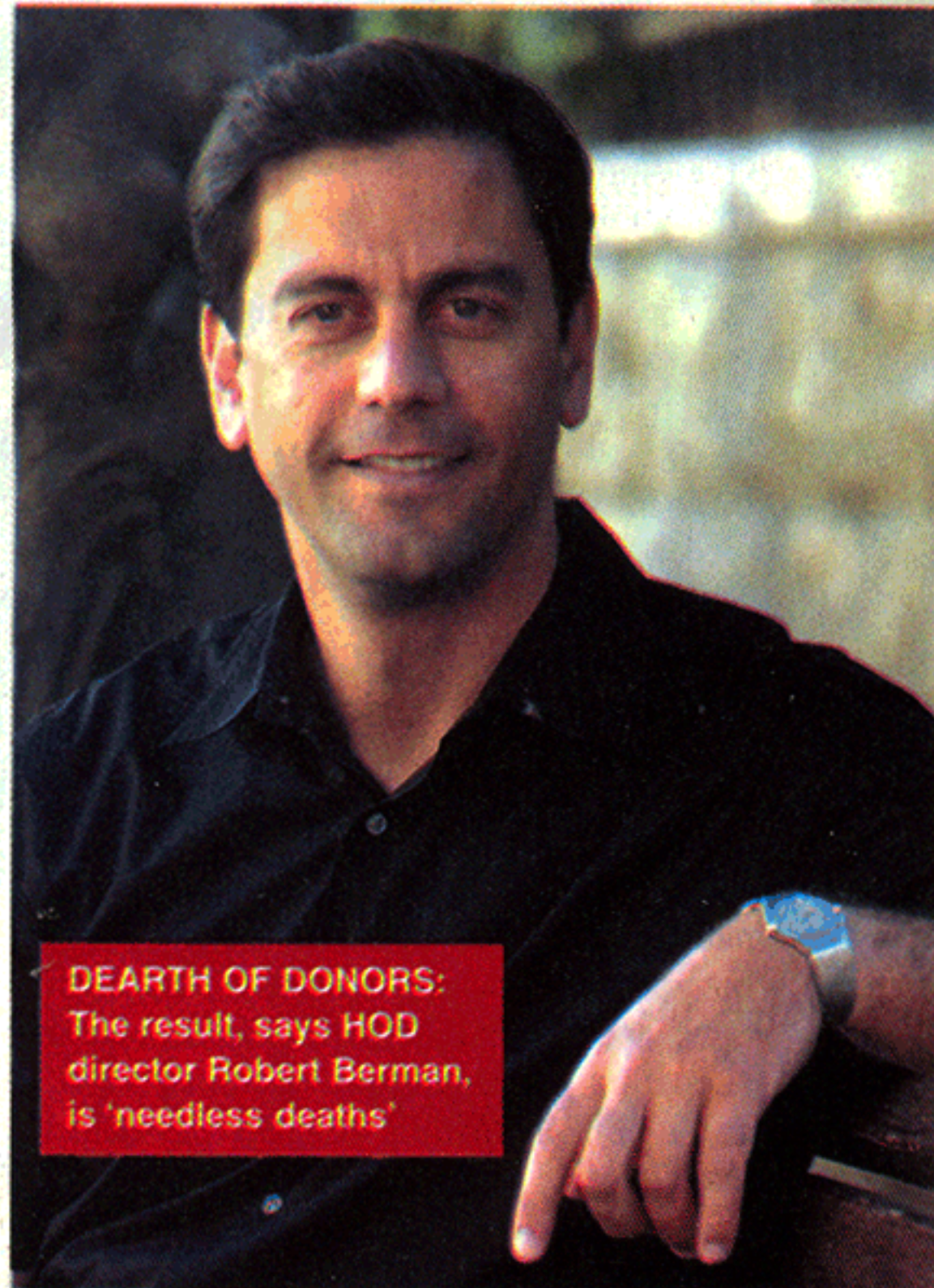
Indeed, Rabbi Dr. Mordechai Halperin, the chief officer of medical ethics at the Ministry of Health, reports that the prevailing opinion among contemporary *poskim* (rabbis who issue halakhaic rulings) is that the saving lives (*pikuah nefesh*) overrides the three prohibitions cited above, with one qualification. "Regarding the proscription on mutilating the dead," he says, "the general rule is that one must obtain the deceased's prior agreement to harvest his organs, which can be assumed if he carries a donor card." The main halakhaic dispute, Halperin stresses, is over the question of how to define death. In the past, the classic determination was that the heart stops beating and breathing ceases. In a state of brain death, the heart continues beating but, because the brain stem has died, the patient cannot breathe on his own and he must be sustained by a respirator.

"This is the key question," says Halperin, "and there are three different halakhaic opinion on it." One follows the traditional determination of cardiac death. The second posits that unless the entire brain is dead, not just the stem, a person is still alive. The third, which is subscribed to by the Chief Rabbinate, defines a person as dead when the brain stem dies and he is unable to breathe independently. And in practice, a family consulting with a rabbi on donating the organs of a loved one might encounter any one of these opinions.

The glaring gap between the local supply and demand for organs has not only sent

increasing numbers of Israelis to seek salvation abroad. It has also given rise to trafficking in these precious commodities. In 2003, for example, the South African police broke up an Israeli-led ring of traffickers who had been paying poverty-stricken Brazilians for kidneys and flying them to Durban for the surgery that benefited mostly Israeli recipients. Retired transplant surgeon Zaki Shapira, who was arrested in Istanbul in

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DEARTH OF DONORS:
The result, says HOD
director Robert Berman,
is 'needless deaths'

May on suspicion of involvement in illegal trafficking, was acquitted of the charges by a Turkish court. But in mid-July a ring of ten people working out of Israel — and imprudently advertising cash for kidneys in the local Arabic- and Russian-language press — was arrested on suspicion of buying and selling organs for transplants done in Ukraine (under a 2006 law that prohibits trafficking in human beings for the purpose of obtaining organs).

And these were apparently not isolated cases; there's a suspicion that, through mediators, Israeli patients have long been buying organs for transplants performed in Turkey, Eastern Europe and the Far East. Until recently, private companies had also arranged for transplants in China, which was widely condemned for taking organs from executed prisoners and has now reportedly closed its doors to "transplant tourism."

An Example to Emulate?

NOTWITHSTANDING THE AZ-raks' unhappy experience in Colombia, other Israelis have returned from transplant surgery there with glowing reports on the level of care and attention they received and recommendations that its system could be a valuable model for Israel.

Sima Rubisa, 60, for example, contracted with the private Israeli medical company Ventex for both the liver transplants she underwent in Medellin, Colombia. She heard about the company after emerging from a coma and learning that her doctors had bumped her up to the top of the national waiting list "but could not predict when a compatible organ would materialize," she says. Biochemist Yehonathan Pouny, 42 and the father of three, also chose Ventex after first talking with the representative of a company that arranged transplants in China. "We were concerned that organs were being taken from condemned prisoners and asked if he could assure us that my kidney would come from an accident victim," he reports. "That company never called back, so my wife and I contacted a number of people who had gone with Ventex, and we were impressed by their experiences."

All these transplants were covered by the supplementary insurance of Israeli HMOs, as Colombia is in no way suspected of a cavalier attitude toward trafficking. On the contrary, says Michael

Martin Levy Hattendorf, the director of Ventex's operations in Medellin for the past five years, precisely because of the high poverty rate in Colombia, its stringent transplant law sets the penalty for buying or selling organs at seven years' imprisonment. It also bars any contact between a recipient or his representative and a donor or his family, and preserves the donor's anonymity even after the fact. "I once innocently offered to pay for the cremation of the deceased, and that too was forbidden," he says.

Yet Colombia boasts the highest donor rate in the world — 51 per 1 million people — which Hattendorf credits to a combination of reasons. First, its transplant law is based on a variation of presumed consent. "Once a person is pronounced brain dead, his body belongs to the state," he explains, "but his organs cannot be recovered if anyone in his family objects." On the average, though, 90 percent of the families do not intervene because cremation is the predominant practice in Colombia, he adds, "and they would rather see the organs of their loved ones survive." On top of this, organ donation is actively encouraged by Colombia's clergy and advocated in the educational system, from kindergarten upward.

"I only wish our rabbis and schools would follow this example," says Pouny's wife, Tali, who particularly recommends meetings with both the immediate beneficiaries of organs and their parents, siblings, spouses and children, "to appreciate not only how many lives can be saved from one death but how the lives of so many others around a recipient are affected by this gift." ●

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Last year, increasing discomfort with this situation prompted the director general of the Health Ministry to issue a directive forbidding HMOs to cover the cost of transplant surgery performed abroad, unless the patient supplied official documents attesting that an organ had been donated without duress or financial remuneration. "The problem is that the directive does not have teeth, for it's not anchored in law," says Prof. Jacob Lavee, director of the heart transplant unit of the Sheba Medical Center outside Tel Aviv. "It was even challenged in a labor court, which issued a temporary order against it."

TO ADDRESS THIS PROBLEM and others in the system regulating transplants, for the past half year a subcommittee of the Knesset's Labor, Welfare and Health Committee has been deliberating a comprehensive, government-sponsored bill drafted by the Health Ministry. The purpose of the legislation, explains Meir Broder of the ministry's legal department, is both to prohibit trafficking in bodily organs and, for the first time, anchor in law all the activities of the NCT, which include the sensitive issue of determining which patient enjoys priority when a suitable organ becomes available. If passed, the

law will prohibit Israelis from selling or buying organs anywhere in the world. But Broder notes that, in practice, penal sanctions will not be applied to either live donors or recipients of trafficked organs, "since we regard them both as victims, not criminals." The crackdown will be on middlemen who thrive from arranging such deals, along with HMOs, insurance companies or any other bodies that fund transplants in violation of the law's strictures.

By mid-July the Knesset subcommittee — chaired by MK Arie Eldad of the National Union party (a medical doctor and a former chief of the IDF medical corps) and advised by leading transplant surgeons and representatives of the Israel Medical Association, the Israel Bar Association's medical ethics committee and the NCT — had hammered out the clauses of the bill, with one cardinal exception. Added to the original draft, at the initiative of subcommittee members, was an innovation unparalleled in the West: authorization for the state to pay compensation to live organ donors. But the Knesset members were unable to bridge glaring differences over the form such recompense should take.

At one pole of the dispute stand MKs Shelly Yacimovich of Labor and Zahava Gal-On of Meretz, who propose that a live donor who suffers damage to his health as the result of his donation will be entitled to reimbursement of the medical expenses incurred to rectify it. At the other stands MK Avraham Ravitz, of the ultra-Orthodox United Torah Judaism party, who suggests that the state accord all live donors a hefty package of benefits. These include a monthly allowance from the National Insurance Institute, a full exemption from the mandatory health tax, the exemption on income tax granted to the blind or totally handicapped, a discount on municipal property tax, both a life-insurance policy and one compensating for any future disability that prevents a donor from working, a tuition grant (to the donor or his children), and free rides on public transport.

As a compromise between these radically divergent views, the Health Ministry is proposing that the state grant a live donor a flat fee (currently mooted at 17,000 shekels, or \$4,000) to cover financial losses due to lost work days or to go toward the premiums on a private or HMO supplementary health-insurance policy and insurance against any future medical disability that prevents him from working. When informed of these ideas, Eric Swim remarks on how far the state has come since the days when it shuddered at the least hint of rewarding a donor

in any fashion. While recuperating from surgery in Israel, Swim recalls, when he casually mentioned that his family was interested in converting to Judaism and wondered whether this was an opportune time and place to do so, one of his doctors admonished him to drop the idea, lest it be construed as a bid for special treatment in return for his kidney donation.

One proposal not included in the draft is Lavee's suggestion that, beginning a year after registering for a donor card, a citizen who learns that he him-

self requires a transplant will be "advanced up the waiting list" to a priority slot. Prof. Eytan Mor, head of the transplant center of the Rabin Medical Center in Petah Tikva, also asked the subcommittee to consider the more far-reaching principle of "presumed consent," which is the law in Austria, Belgium, Argentina and Spain. Presumed consent treats everyone as a potential donor unless he has noted his objection to this status should he ever be pronounced brain dead. Yet Mor noted that, even with the law backing them, doctors in these countries customarily seek the approval of the deceased's family before recovering organs.

At an early-July meeting of the subcommittee, the opposing camps on the compensation issue were still slugging it out, though it had already been decided to present all three proposals to the full Labor, Welfare and Health Committee to make a choice. Yet the Health Ministry's legal counsels have already warned that if Ravitz's

proposals prevail, the ministry will withdraw the bill. "What Ravitz suggests is tantamount to institutionalized trafficking in organs," Broder fumed to *The Report*. "There's no other way to put it."

Halperin points out, however, that while the position on the Continent rejects compensation as immoral, this is no longer the only view in Britain. And the halakha, he adds, supports the reading that "there's no reason why a surgeon and hospital should be paid for their services while a donor is required to save a life for free." Beyond this, he posits, "forbidding a reward under these conditions is viewed by the halakha as exploitation of the donor." But translating this position into practice, he stresses, must be contingent upon a creating a means to fully ascertain — through a police investigation, if necessary — that a donor is not being coerced, by threats or in any other way. "And until such a system is in place," he says, "paying for organs should be strictly outlawed."

Other voices in Israel are unabashedly calling for the law to allow payment for organs. To eliminate trafficking, says Yair Skalsky, chair of the Bar Association's medical ethics committee, "I would like to see a system of institutionalized payment, coordinated by the state." It would bar any contact between donors and recipients, he elaborates, and ensure that the sole criteria for the allocation of organs are medical. "But I don't think it matters whether payment to the donor is in the form of money or in benefits, as long as it competes with the going rate on the black market."

WILL CLASHING VIEWS ULTIMATELY foil the passage of a transplant law? Eldad, who says that raising the rate of organ donation is in everyone's interest, is confident that the bill will emerge from the committee in the foreseeable future, "though I can't say in which of the three proposed forms," he qualifies. If, at any stage, the Health Ministry withdraws it, he continues, "I'm sure it will be resubmitted as a private member's bill." The real test, he predicts, will come in the Knesset plenum, where coalition discipline will undoubtedly be invoked in voting on the bill. "I just hope that the final version isn't so bland that we'll have a law but it won't improve the present state of donations," says Eldad. "All our work will have been in vain if the Knesset chooses to be supremely moral and people continue to die for lack of organs." ●

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COLOMBIAN COMPLICATION: Shiran Azrak couldn't afford to wait for a kidney in Colombia