HED: Transplanted

DEK: How undocumented immigrants with terminal kidney failure fight to navigate a health care system that doesn’t acknowledge they exist

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[Teaser VIDEO here?]

\*\*\* INTRO \*\*\*

**America’s 11.3 million undocumented immigrants** -- more so than any other group in the country -- struggle with health disparities. They don’t qualify for federal programs like Medicare; Their jobs don’t carry benefits; And years without primary care often lead to chronic illness. Emergency rooms are their only doctors.

Life-saving operations, like organ transplants, often fall out of reach for the undocumented; not because of their immigration status, but because of their wallet. They can’t pay. End-stage kidney disease, treatable with a transplant, is an especially slow and painful killer for 6,480 undocumented every year living on dialysis. Most can’t afford to get on the transplant list or even receive a kidney from a living donor.

This is the story of how five men -- connected by turns of fate, stomping feet, and profound acts of charity -- have worked around the kidney transplant system to save one another from slipping through the cracks.

\*\*\* SECTION 1 \*\*\*

**Friends don’t ask friends for vital organs**. But in 2010, Donald Kagan needed one -- and time was running out. The small cysts in his belly had finally begun to incapacitate both his left and right kidney; what had started as one tiny stone a decade earlier. It had since developed into terminal renal failure. So he wrote letters to two friends, asking for a favor he could never return. “It was the one of the most difficult things,” said Kagan, 50.

The first reply was a sincere rejection: high blood pressure. The second never came.

He had liked living in Nicaragua, in his peaceful home, a northern city called Estelí. It’s where he met his wife, where he worked, volunteered and where he had made life-long friends. But he moved back stateside San Ramon, where he could buy a little more time while on dialysis.

[Main VIDEO of Donald here]

There are 26 million people In the U.S. with kidney disease and 700,000 are end-stage, enough to fill Dodger Stadium 12 times with people like Kagan. Each one needs a kidney transplant or they’ll die, sooner or later.

The system is difficult to navigate. First doctors at a transplant centers have to approve you as a “good candidate for transplant.” Once on the list -- called the kidney allocation system -- you’re ranked on a sliding scale. Kidneys get a score, too, based on their previous owners’ health history and demographic information, like age. Then, a federal contractor called United Network for Organ Sharing, or UNOS, regulates the list, matching kidneys with patients at 270 different transplant centers around the country.

After his diagnosis, Kagan walked into the transplant center at the University of California, San Francisco and then through a labyrinth of tests, forms and phone calls over two months. The hospital passed his information to UNOS, which gave him a profile and score based on biological factors -- his blood type, time spent on dialysis, transplant history, symptoms.

UNOS has to balance each kidney’s utility -- the most live years inside a living body -- with equity -- making sure all individuals have the same access to a kidney. It’s an ethical calculation that can at times seem contradictory and even arbitrary, especially for those who miss out. Every day, 13 people die while waiting for their number to get called.

“We're always looking to make sure we're not disadvantaging any group of people,” said Anne Paschke at UNOS. “We’re doing our best to make the most use out of any organ [with] what’s available -- considering a number of people will die every day while waiting, while also making sure that all groups of people have a fair chance at getting a transplant.”

Hospitals describe the list as a pool of patients. Those patients reshuffle every time a new kidney becomes available -- about every 10 minutes -- based on who might be the best match.

But transplant centers consider another factor in deciding who gets in the pool: your wallet. Can you pay for the surgery and, perhaps more importantly, the lifetime of treatment afterwards? A patient needs to be able to afford the medicine that prevents her body from rejecting the organ. Otherwise that transplant center isn’t making the best use of that organ.

If you’re finances are insecure because you’re uninsured or undocumented, your chances of getting on the list shrivel. THIS MANY undocumented people with renal disease are not on the transplant list. Medicaid and similar state-programs have extended insurance coverage to millions of low-income families. THIS MANY people in California alone have received organ transplants paid for by Medi-Cal. But for the state’s over TK undocumented in need of a kidney transplant, WHAT PERCENT will likely never see the operating table.

Paschke said that although “social factors” aren’t weighed in a kidney’s allocation, “being able to pay is a big issue. If you can’t afford these super expensive drugs, chances are you'll reject the organ.”

“When [transplant centers] are doing your evaluation, they look at everything about you and then make a decision. And that's where the ability to pay comes in.”

Lucky for Kagan, he had insurance through the nonprofit where he worked. In March, 2010, he was accepted onto the list. He was a good candidate for transplant -- but his transplant center estimated a 10-year waiting time. Medical urgency, he learned, is just one of many factors tossed into the calculation. The U.S. has a bank of kidneys with about 20,000 available at any given time. But demand has soared past it: For every one kidney in the system, there are 4 other people Donald Kagans competing to receive it.

Kagan thought he’d die while waiting for his number to get called. “I was depressed,” he said. “I had lost hope.”

Then, two months later, he was getting dinner with an old friend from Nicaragua, Osvaldo Rayo. At the time, Rayo wasn't a citizen, but a resident in the U.S., living here as a resident. They talked about Kagan’s organ prospects. Rayo, 53, saw that his friend had already started giving up hope. Then, Rayo unceremoniously offered one of his kidneys. He remembers the simple exchange well.

“Are you sure?” Kagan had asked.

“Yes.”

“Really sure?”

“I’m sure.”

\*\*\* SECTION 2 \*\*\*

**Four months later, in September of 2012**, Kagan and Rayo lay in separate hospital rooms at UCSF. Donating a kidney is a relatively easy process compared to treading water in the national recipient pool.

The kidney was the first organ donated from one living soul to another. In 1954, surgeons at Peter Bent Brigham Hospital in Boston successfully transplanted a kidney from one twin into his identical brother. Today, more than 6,000 people like Rayo donate a kidney every year. One in four aren’t directly related to the recipient.

[VIDEO of Osvaldo saying why he decided to help Donald.]

First the transplant center drew Rayo’s blood: O negative. A universal donor. Next, the doctors quizzed him on his medical history. All clear. Then, he and Kagan answered a battery of questions on their relationship to one another. Transplant centers have become increasingly vigilant of “organ tourism,” situations where recipients pay donors for black market organs in other countries. It was clear that was not the situation here.

Finally, the transplant center asks the ever-crucial: Who’s going to pay?

Kagan’s insurance covered both men, including the medical evaluation, procedure, and post-op care. It’s not uncommon for non-residents like Rayo often give organs in the U.S., paid for by the recipient. In 2015,  436 of the 30,128 organs came from “non-resident alien” donors.

But it’s a much different situation on the other side of the operating room. Undocumented immigrants -- the largest category of non-resident alien -- have disproportionate trouble receiving organs. Some face more delays after waiting on the list. But most can’t get on it or even receive from a living donor, usually relatives.

“Undocumented people can donate organs but you can’t get a transplant,” said Betzabel Estudillo at the California Immigrant Policy Center. “You can’t be on that waiting list. I’m sorry but it’s pretty fucked up.” [VIDEO if Rosa Olivas, Osvaldo’s wife, about undocumented being able to donate.]

“People are dying because they don’t have money. And they don’t have years -- they don’t have time for policymakers.”

Undocumented immigrants face a cycle of health care disparity in the kidney transplant system. They don’t have health insurance because they don’t have steady work (and they don’t qualify for Medicare). They often don’t have steady work because of their chronic illness, which is a result of poor access to healthcare. And chronically ill patients without money for postoperative medicine or ready access to follow-up care don’t make for “good candidates.” The finite number of kidneys, national regulators reckon, won’t get great mileage in an undocumented body. As demand outpaces supply by a larger margin each year, transplant centers face increasing pressure to make the best use of those organs they do have.

Every healthcare professional interviewed for this article said that there is categorically no language discriminating against undocumented immigrants in the transplant system. But, they conceded, there is a direct correlation between citizenship status and access to organs.

“Some people in the transplant community would suggest,” said John Murray at the UC Irvine transplant center, “that the efforts from CMS [Centers for Medicare and Medicaid] has effectively suppressed transplant centers’ ability to give kidneys to people who might not be A+ candidates.”

He said the federal government expects transplant centers to yield certain return on the organs they distribute -- an expectation that leads to conservative choices. Many bubble candidates are turned away. “Most places will tell you it is a concern, if they’re being honest,” he said. “[Transplant centers] are entrusted with an organ, and you want to make sure it’s used and cared for properly.”

“Most people who end up getting transplants are paid through Medicare,” he added. “I frankly don’t know what payment options are available for people who aren’t insured and who don’t qualify for Medicare.”

Of the 11.3 million undocumented immigrants in the U.S., an estimated 6,480have end-stage kidney failure. Though transplant centers and UNOS may not discriminate based on citizenship explicitly, legal status prevents disproportionate numbers of immigrants from organ access because most work in precarious industries without steady pay or health insurance. And they have no federal healthcare program to fall back on. There is no sweeping Medicare safety net for the undocumented.

Ole Dierks, a nephrologist at Sutter Health in Oakland, said he sees the disparity all the time, where it ends up costing the state more to keep undocumented immigrants on dialysis than providing the operation. “I've had numerous patients,” he said, “who won’t be eligible for a transplant because their transplant medication is not paid for and they won't be able to have the funds basically pay for those transplant medicines themselves. So it's a little bit of a schizophrenic situation, where the overall cost of a patient who has transplanted is less than the cost of somebody who dialyzes. But for some reason, their medication is not paid for, so they basically won't have the benefits of a transplant.”

“So your survival is impacted. You won't live as long.”

\*\*\* SECTION 3 \*\*\*

The phone rang at 11 p.m., one September night in 2012. Half-asleep, Jesús González, 39, reached across his body to pick it up, tugging at the catheter jetting out from beneath his ribs. A tube snaked into a machine next to his bed.

Someone from UCSF on the other end of the phone told him there was a kidney waiting for him in San Francisco, but he had to come in immediately.

González unhooked himself from the machine and rushed to tell his wife and toddler. They packed into the car and headed out of their East Oakland house -- toys and recycled bottle in piles behind a wrought-iron fence in the driveway -- and toward the city, wary, but hopeful.

The first time he got a similar call seven months before, things hadn’t gone well.

[Main VIDEO of Jesus]

González was waiting on the kidney transplant list for almost eight years. Still healthy enough to work, he had insurance through his metalworking job at Berkeley’s Pacific Steel Foundry. He was a good candidate -- even though he was undocumented.

UCSF operates one of the largest kidney transplant centers in the world, with more than 5,200 patients and only some 350 kidneys. After the Bay Area media caught wind of Navarro’s story, the hospital released a statement saying that there had been “a misunderstanding.”

“Due to the complexities of the current health insurance industry,” the hospital said, “[his immigration status] was a concern for UCSF because it increases the risk that Mr. Navarro will not be able to continue to be insured and therefore not receive the follow-up care and medication needed to stay healthy after a transplant.” [mini VIDEO of Donald about UCSF’s mistake]

According to UNOS, however, transplant centers are not supposed to revise a candidate’s placement on the list after they’ve been accepted, regardless of the financial stability.

But that’s what happened.

“Mr. Navarro’s status on the waiting list was changed to ‘inactive’ as a result, which means that he would maintain his place on the waiting list, but would not receive a transplant even if he reached the top unless he had a reasonable coverage plan in place.” Navarro had taken that to mean he was kicked off the list. But the hospital argued that it was a precaution given his uncertain financial situation, which is curious given that, at the time, he had full coverage from his work. The hospital declined to comment further.

“This situation underscores the many obstacles all transplant candidates face,” the hospital said. “These obstacles can be more difficult for undocumented individuals to overcome.”

Carmen Peralta, a nephrologist at UCSF who was not involved with González’s case, said those obstacles often start at the primary care stage. Early indicators of kidney disease, like high blood pressure, go undetected because undocumented people don’t have access to insurance that covers checkups. A condition that could be treated and cured develops into a deadly disease. “Not having insurance is a gigantic predictor of outcomes,” Peralta said. “If you don't have insurance, you’re at much higher risk of having adverse outcomes.”

“If you’re undocumented,” she said, “you don’t qualify for federal insurance. Each county or city has to decide what they’ll do about it.” They end up getting primary care at the emergency room. “And by law`nobody can be turned away from an emergency room.”

Some cities and communities have taken it upon themselves to bring preventative care to the undocumented and uninsured. The Contra Costa Cares pilot health program, with $1 million in pilot funds from the county and local hospitals, gives primary health coverage to low-income, uninsured and undocumented people. It’s incumbent on the community, county controller John Goia said, to provide healthcare to the people living in it. “It saves money and lives.”

After he left the hospital, González had even more to overcome. Only one month earlier, he had been laid off from his job along with about 215 others during an immigration audit at the machine shop. Although he didn’t lose his insurance right away, he may soon.

González said he has some coverage from Medi-Cal and some area nonprofits are getting the rest.

Medi-Cal covers adult undocumented immigrants’ daily dialysis, [according to the Department of Health Care Services](http://healthconsumer.org/Medi-CalOverview2008Ch14.pdf). But it does not cover a transplant or post-opp immunosuppressant (anti-organ rejection) drugs for them. Navarro would now have to pay the full $263,000 for the surgery, out of pocket, not including medication. The Pew Research Center estimates that immigrants make up 6 percent of the state’s population and 10 percent of the workforce. But adult undocumented immigrants only have limited access to Medi-Cal, not the full suite of coverage.

Most other states only offer emergency dialysis under their Medicaid programs. “In a sense,” one nephrologist writes in the American Journal of Kidney Diseases (AJKD), “my undocumented patients are lucky to be in California.”

“It is up to the individual states to decide what constitutes ‘life-threatening.’ In most states, only those undocumented immigrants with potassium levels high enough to stop their hearts from beating are guaranteed emergency dialysis treatment.” But most with kidney failure would argue their disease is most definitely “life threatening.”

Let down by the transplant system, González fell into the cycle of so many others in similar straights: undocumented, sick, weak, out of work and without money to get out.

Most undocumented with end stage renal failure are younger and healthier than their American neighbors, [according to studies in the AJKD](http://www.ajkd.org/article/S0272-6386(12)00852-9/fulltext#tbl4), with higher rates of living donors willing to spare an organ. Advocates often point out that most undocumented immigrants in need of kidneys have their own donors already lined up. They wouldn't need to dip into the bank on the list.

“Because the undocumented community tends to be young and healthy,” [UCSF nephrologist Vanessa Grubbs writes in an editorial](http://content.healthaffairs.org/content/33/2/332.long), “the few with kidney failure would likely have a healthy friend or family member willing and able to donate one of their kidneys. In these cases, a transplant would not take a kidney from the limited pool of donor kidneys.” Navarro had turned down his wife for years, even though they’re a match. “I cared about her health,” Navarro said. “I told her that we should wait, that something was going to come up.”

Worse still, his odds of surviving end-stage renal failure plummeted by 60 percent once a transplant was taken off the table. Navarro’s life expectancy dropped 15 years in an instant.

The Bay Area media picked up his story and sparked some temporary outcry. The national non-profit Change.org started a fundraising campaign and La Clinica de la Raza offered to pay for his postoperative medicine. Others, too, gravitated toward the case.

Donald Kagan read *The Mercury News’* story, “No transplant for dying dad who is illegal immigrant,” and knew he wanted to help. It had been two years since Rayo saved his life, and now, he reckoned, was as good as time as any to pay it forward. “Because Osvaldo helped me, of course I have the obligation of helping someone else,” Kagan said. He got in touch with González, and, that very same day, they met in person.

Kagan became González’s liaison to UCSF – where Kagan had gotten his transplant a couple years earlier. For months, he negotiated with the hospital on Navarro’s behalf. Staff there had already taken steps to solving the González situation -- something of a public relations disaster.

Then on September 25, at 11 p.m., UCSF called with the news: González’s new kidney had arrived.

This time, UCSF didn’t ask about González about his social security number. The hospital worked with the nonprofits -which were paying for his Kaiser insurance- and Medi-Cal to cover the cost of the surgery and the medicine.

[VIDEO of the medicine Jesus takes daily]

González’s wife Angélica said she’s thankful because everything went smoothly the second time around. Her husband has two functioning kidneys -- three total, doctors left in the bad one. He takes about 20 pills per day, the regimen for the rest of his life. “I learned to value life,” she said while holding her youngest daughter in her arms. They have three children; the youngest has autism and requires special care. González watches them every day. “I’m not afraid of poverty,” Angélica added. “I’m not afraid of not having stuff. The most important thing for me is health. Without health, there’s nothing.”

\*\*\* SECTION 4 \*\*\*

**Hugo Huertas, a 30-year-old undocumented factory worker in Tracy**, was blindsided at once by his diagnosis, and then by his cold reception in the sterile world of kidney disease. [VIDEO of him saying that when he first knew about it he feared from his children]

The first step for any kidney patient -- after coping with the diagnosis -- is usually getting on dialysis. When your kidneys fail, they can no longer filter out waste through urine. Dialysis, “a miracle of medicine,” as one doctor described it, replicates the process artificially. The side effects of waste buildup can be mortal.

Huertas had insurance through his work at at a powder paint company. Kaiser Permanente is both an insurance provider and hospital -- but not a transplant center. After his diagnosis in MONTH of 2012,  Kaiser referred his care to UCSF, where he’d begin treatment. “But when I called to make an appointment,” he said, “they denied it because I didn’t have a social security number.” UCSF again declined to comment, saying in an email, “Our policy is that we determine care based on medical need, not immigration status.” [VIDEO of Hugo about ucsf]

Then, in WHEN, he lost his job at the paint factory (he thinks because of his condition, but was never able to confirm that.) Kaiser pulled his insurance the next day.

The Spanish-language news channel Telemundo aired an episode about Huertas’ case WHEN -- his sister had tipped them about UCSF again refusing care for an undocumented patient. He said the hospital called him back shortly after, apologized and put him on the list. UCSF declined to comment on the details of Huertas’ case.

But he still wasn’t on dialysis and his kidneys started failing at an alarming rate. He said that he didn’t pursue Medi-Cal coverage because he knew it wouldn’t cover his surgery should his number get called. Huertas wanted Kaiser back. But he was out of work, without insurance, and his kidney function had fallen 80 percent. He heard about Navarro’s almost identical struggle with UCSF earlier that year and decided to reach out. They met that same day.

Navarro told him who to call: Donald Kagan, who had become something of a kidney health advocate for the undocumented in California.

“He was getting very sick,” Kagan remembers. Huertas needed dialysis immediately. Kagan started paying for the Kaiser health insurance himself, out of pocket, to cover the cost of his dialysis until he could find an alternative. In May of 2014, Huertas was on dialysis paid for by Kagan. Shortly after, the two contacted the National Kidney Foundation, which can offer third-party insurance payments for those out of work and unqualified for Medicare. The foundation agreed to pick up where Kagan had left off and fund Huertas’ dialysis through Kaiser.

HOW MANY UNDOCUMENTED ARE WITHOUT DIALYSIS COMPARED TO OTHERS. Dialysis is a temporary solution that sometimes last years. Around 80,000 people die on dialysis each year. Sooner or later, kidney disease turns terminal, and patients need a transplant.

[VIDEO of Hugo explaining how the dialysis machine works]

Huertas needs a kidney -- a couple potential donors have offered. But first, he needs coverage.

He’s considering applying for Permanent Residence Under Color of Law (PRUCOL), a federal category that wouldn’t give him a legal status but might qualify him for more coverage under Medicaid. That application means telling Citizenship and Immigration Services (USCIS) that he’s here and undocumented. USCIS then responds with a notice: either you’re already on a deportation watch list, or you’re not. If you fall into the latter, you’re ostensibly protected from deportation.

Many undocumented, understandably, are afraid to apply and disclose their status. Huertas filled out the form, but he never submitted it. It’s sitting on his kitchen table. [VIDEO of Huertas saying he’s too afraid to apply to PROCUL.]

By April he’d lost a lot of weight. Solid food and liquid have become hard to keep down. (Nausea is a constant symptom of kidney failure.) He’s working with Kagan on his PROCUL application, still wary of what might happen after telling the government he’s here and undocumented.

Sooner or later he will have to apply to PROCUL, Huertas said. In the meantime, “I’m going to keep waiting on the waiting list.”

\*\*\* SECTION 5 \*\*\*

**Many sick immigrants suffering from renal failure move to California** because of its political climate. It also has the most transplant centers, government funding and a landscape of nonprofits that help immigrants find health care.

Last year Senate Bill 4 passed, extending all Medi-Cal coverage to undocumented children 18 and under, kids who could previously only access limited care: dialysis but not a transplant, for instance. Now, an estimated 170,000 undocumented kids have full access to Medi-Cal, including kidney transplants.

The Medi-Cal expansion for undocumented children is exclusively state-funded and is expected to cost the state Department of Health Care Services about $132 million annually.

"This is a major investment that California is doing, and it's completely the reverse of what we’re seeing at the national level," state Sen. Ricardo Lara (D-Bell Gardens) told the [*L.A. Times* in October of 2015.](http://www.latimes.com/local/political/la-me-pc-california-immigrant-healthcare-20151009-story.html)

"California stands out," he said. "It says we are not going to buy into that rhetoric that’s divisive."

Many undocumented people, adults and children, move to California for that very reason. They hope to find the care they need in a political climate that’s more welcoming than other states. There are 2.67 million undocumented living in the state, and 1,440 of them have kidney disease.

The California Health Care Foundation [estimates a quarter of the 3.8 million uninsured Californians](http://www.chcf.org/publications/2016/03/californias-uninsured) under 65 are not eligible for coverage because of their citizenship status. Half have incomes low enough to qualify for Medi-Cal.

[VIDEO of Irving introducing himself]

Irvin  Xochitla, 22, had lived in Atlanta since he was 8 month old. He was diagnosed with renal failure at 13. Every week for five years, he got a call from a local clinic to set up a checkup and dialysis appointment. Georgia’s state Medicaid program covers certain services for undocumented children, including dialysis. Then, after his 18th birthday, the calls stopped. He reached out to the clinic to find out why, “and they were like ‘oh, you’re no longer admitted in this facility.’” Unlike California, Georgia cuts off state-subsidized dialysis treatment for adults. [VIDEO of Irvin talking about how the disease affects him on a regular basis]

Xochitla had begun coughing up blood, losing his breath regularly and suffering seizures. The toxins in his body that dialysis had circulated out for years were now accumulating inside. “What am I supposed to do now?” he thought. He didn’t have a Donald Kagan in Georgia. He packed his things and headed West to Los Angeles in March of 2012, leaving his mother and brother behind. He has seen them just once since.

He now lives in a side-room in his friend’s Boyle Heights apartment, not healthy enough to hold any sort of steady job while trying to attend community college. He’s getting dialysis treatments through Medi-Cal. “Without money,” he said, “it’s kind of hard to get food. Right now I’ve only been eating once a day to save money and to save for buses to go to school.”

Xochitla and Kagan spoke once on the phone. He told Kagan that he’d tried and failed to get on the waiting list because his local transplant center turned him down for lack of funds. He hasn’t yet qualified because Medi-Cal won’t cover the surgery or medicine. So he’s hoping to fund the operation himself, which usually cost $263,000, before the postoperative medication. He’s raised $3,756 so far in donations on [a GoFundMe page](https://www.gofundme.com/FundingforIrvin).

Kagan pled with him to find a new transplant center that might have more wiggle room. Surely he could find funding and eligibility elsewhere. Xochitla seemed uninterested, tired at the idea.

Depression, experts say, is the debilitating passenger alongside many chronic illnesses like kidney disease. The symptoms, side effects, and constant medication make daily life more of a maintenance exercise than actually living. Xochitla takes seven pills with every meal and one injection every night, before the nine hours of dialysis. It’s hard to keep a job with the burden of fatigue, nausea and almost regular trips to the emergency room, let alone mental health upkeep.

“You experience the spectrum of human emotion at all times,” said Joseph Perales at La Clínica, Casa del Sol in Oakland. La Clínica organizations all over California offer different health and legal services to immigrants. “You go into this maintenance mode of existence through dialysis. It impacts your mood in a severe way, managing all sorts of anxiety depression, grief and loss. It’s all very hard to manage.”

More healthcare reforms -- the follow-ups to SB-4 -- are currently jostling through Sacramento. Senate Bill 10 would allow undocumented adults to receive comprehensive Medi-Cal -- including kidney transplants and medication. It will also grant all Californians, regardless of immigration status, the ability to buy coverage through Covered California with their own money by requiring the state to apply for a federal waiver.

That could be big news for people like Xochitla, those who fell through the cracks, toiling in obscurity outside the kidney transplant system. They could finally become “good candidates.”

“On dialysis I don’t feel like I’m on my full potential,” Xochitla said. “I know I can do more because this illness, it’s keeping me at a certain place. I want to move on beyond that, push myself, but the more I push myself, I’m pushing my body, and my body can just give up on me.” [VIDEO of Irvin saying this.]

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