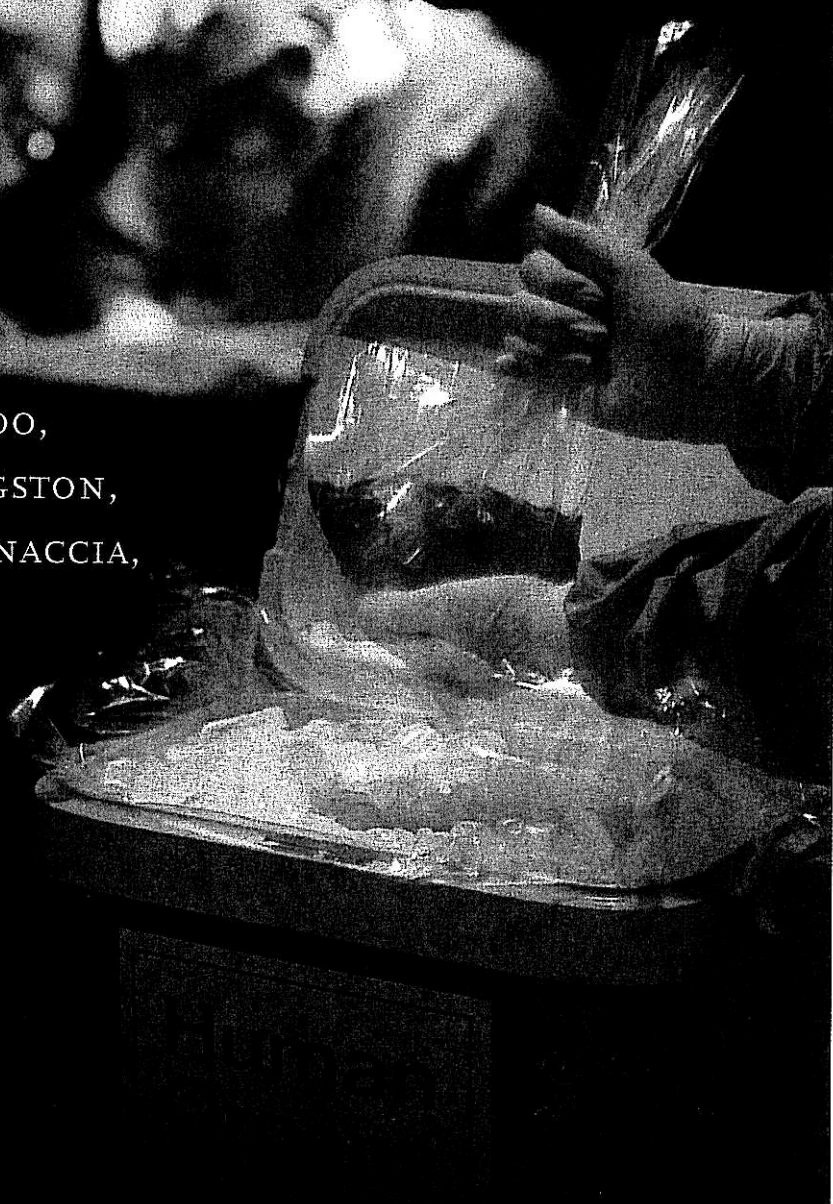


# A Death Retold

Jesica Santillan,  
the Bungled Transplant,  
and Paradoxes of  
Medical Citizenship

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**AMERICA'S ANGEL OR THIEVING IMMIGRANT?  
MEDIA COVERAGE, THE SANTILLAN STORY, AND  
PUBLICIZED AMBIVALENCE TOWARD DONATION  
AND TRANSPLANTATION**

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Organ donation has always faced a difficult battle in vying for positive media coverage. At the center of key tensions over how we tend to think about the goals of modern medicine and how we think about the human body, organ donation has often produced a profound ambivalence. Historically, print journalism and television coverage has often utilized almost Frankenstein-like images of "harvesting" organs to rebuild a defective human body while, at the same time, portraying organ transplants as miracles of modern science and the sole hope for life for the many thousands of people on the waiting list. Jessica Santillan's so-called botched transplant generated an intense media attention from February to March of 2003 that reflected this deep-seated ambivalence. News coverage first centered on a report of the clinical story: a terrible error and a failure to double-check medical tests lead to the near-death of a young Mexican girl at Duke University Medical Center in North Carolina. However, when a new set of organs became available almost immediately, the coverage began to question the fairness of the organ allocation system: how were doctors able to procure organs so quickly when thousands of other patients were waiting? These stories and commentary soon turned to ugly questions about why organs from an American citizen were used to save the life of an undocumented immigrant when so many American citizens were dying while waiting for transplants. In its slow transformation from a story of lifesaving transplant surgery into a vexing scandal laden with blame and accusation, the Jessica Santillan case added to the corpus of mixed messages in the media and throughout America about organ and tissue transplantation.

This essay examines shifts in media representations as the Santillan story unfolded in national and local media. We do not tackle critical questions about the motivations that shape these representations, nor are we interested in

United States covered the story. Rather, in the following pages we elucidate the overarching narrative of the Santillan transplant, how the story emerged into the public sphere, how it changed over time, and how authors and commentators articulated the meaning of this case. On such high-tech medical and scientific topics, Americans tend to rely heavily on representations in national media, especially because most readers have little personal experience with the issues; in these instances, then, such accounts play a disproportionately powerful role in shaping opinions.<sup>1</sup> Therefore, a national examination of the Santillan coverage provides a crucial starting point for understanding how key characters in the drama were presented to most Americans, and how these characters themselves came to embody different features of the publicized ambivalence toward organ donation and transplantation. Moreover, this national examination also allows us to follow the rapid shifts, instabilities, and ambivalences in the public discussion not only of the Santillan drama and organ donation and transplantation, but also of immigration—a theme that became a potent backdrop of the public commentary (see figure 1).

Remarkable events associated with a particular phenomenon create a spike in media coverage, and they also create potential turning points in representations of the phenomena.<sup>2</sup> The case of Jessica Santillan represented exactly such an extraordinary event that brought to the surface of public discussion deeper conflicts about donation and transplantation. While many other cases of organ donation have captured public attention for a few days at a time, in this instance media coverage lasted much longer than one or two days. The most intense reporting spanned approximately two weeks, from February 17 to March 5, 2003 (see figure 2); but articles referencing Jessica Santillan could still be found six months later. We used a television monitoring service called ShadowTV to gather data on this coverage, and we also performed routine online searches for national and regional newspapers stories. We focused principally on coverage of Jessica's story after the initial transplant on February 7. As a media event, the story was nevertheless short-lived, beginning with intense reporting on February 17 after the public disclosure of the error. By February 28, virtually all television coverage ended whereas heavy print coverage continued until March 27, 2003. Overall, our research uncovered 97 unique print stories and 65 unique television stories that featured or referenced the Jessica Santillan case, resulting in 162 stories for analysis.<sup>3</sup>

What were the major recurring patterns of coverage? And how did the themes (and the intensity of coverage) change over time? The telling of the

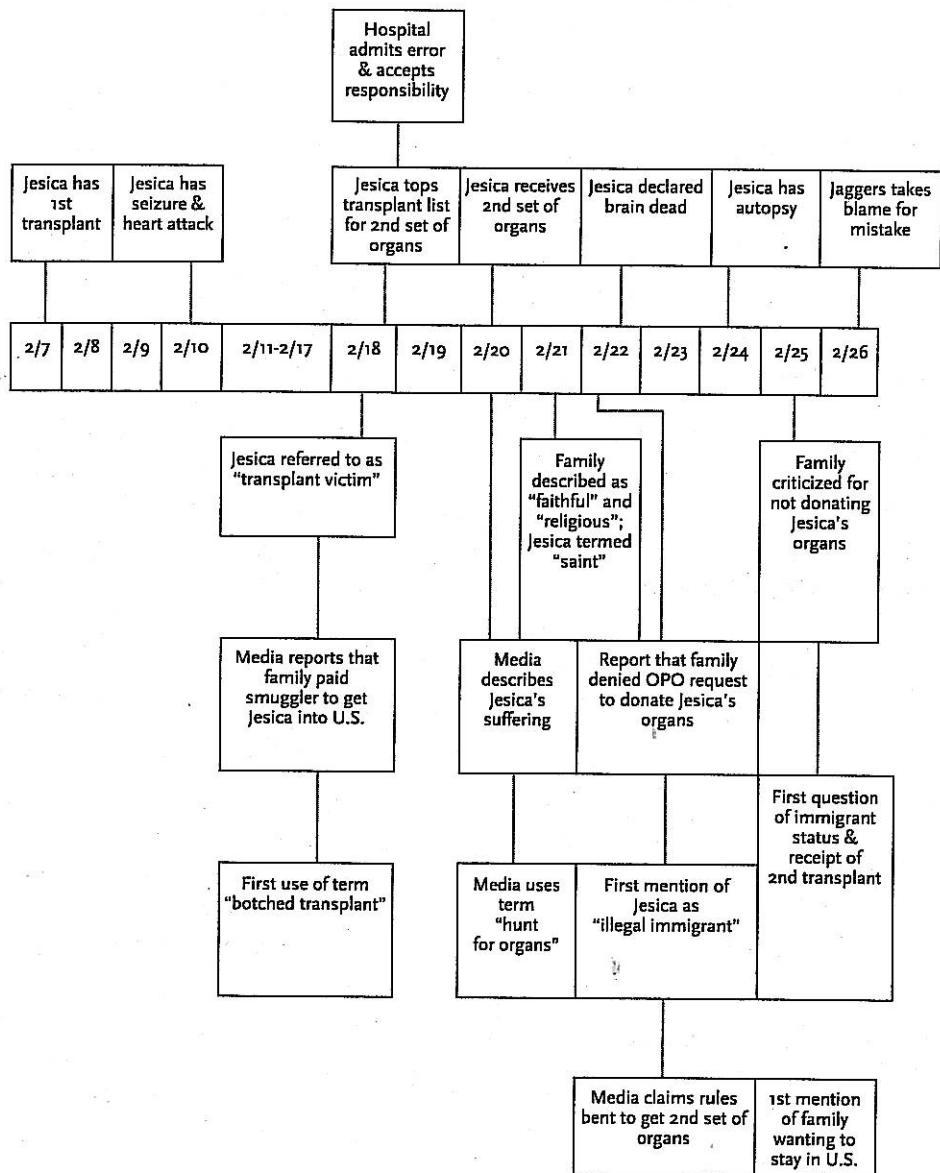
family (particularly her mother Magdalena), her patron Mack Mahoney, Duke University and its spokespeople, and other key actors such as the United Network for Organ Sharing (unos), and the coverage also produced linguistic themes that anchored the story. In the creation of social representation, processes of anchoring (that is, finding language to describe the new phenomenon) and objectification (in which key concrete images or prototypes are attached to the phenomenon) are crucial.<sup>4</sup> Over time, despite internal contradictions in the news reporting and commentary, despite wide variations in how the story was told in different parts of the country, and despite large differences between television and print media, a “consensual reality” of the case took shape.<sup>5</sup> A number of actors appeared repeatedly in news coverage, and as their influence on the circumstances changed, so did the media’s portrayal of those individuals.

### **MEDIA REPRESENTATIONS OF JESICA SANTILLAN**

The Santillan case played out like a drama in which media portrayals of concealment, deception, power, moments of joy, and tragedy captured the attention of the public. Yet, despite most of the action, the central actor, Jesica Santillan, was a silent symbol, characterized either as a victim/saint or, conversely, as an illegal immigrant. She would not be presented as a full person until after her death.

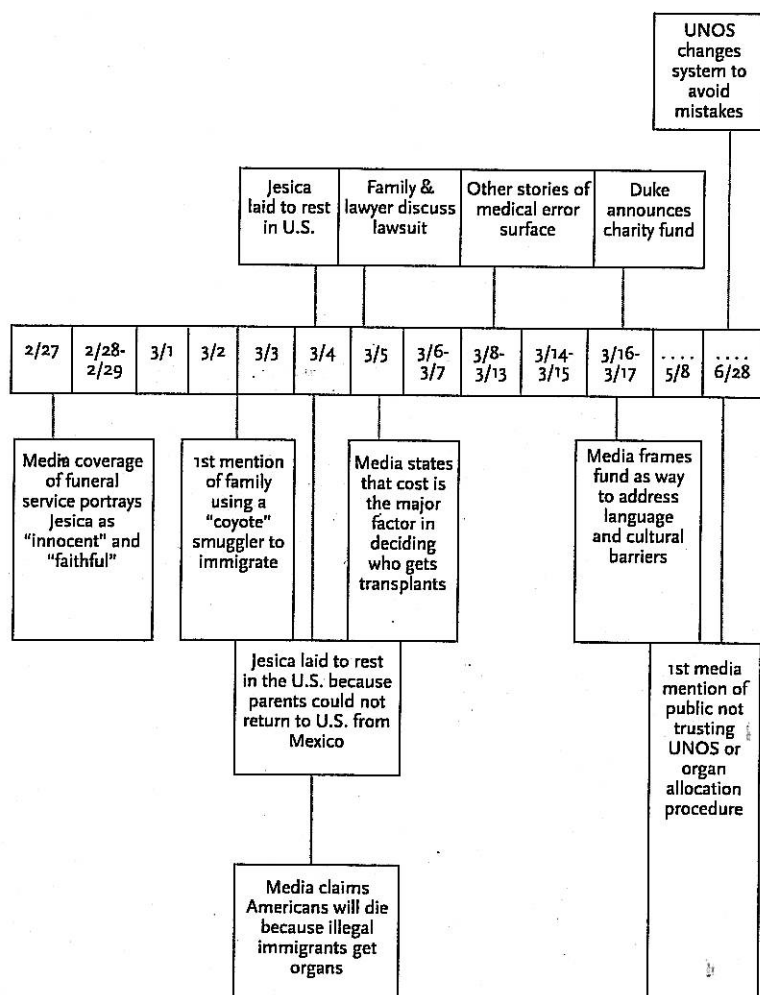
When television and print media first introduced their readers and listeners to Jesica in a comprehensive way, she had already undergone the first transplant with mismatched organs almost ten days earlier, and lay in critical condition. A second transplant offered her only chance for survival. While her family and her advocate Mack Mahoney petitioned the public for help saving Jesica’s life, doctors contended that there was little that could be done. Jesica was small, frail, and barely clinging to life; and she was surrounded by a desperate family, apologetic doctors, and a chastened hospital. In one account after another, media accounts implicitly invited the public to pray along with Jesica’s family. And when Jesica received the second transplants on February 20, her family and friends were portrayed as happy and grateful. At the same time, however, the coverage that had encouraged communal hope, began to question why a frail patient with such a slim chance of survival had received another transplant. Part of the explanation was the “sickest first” policy that determined eligibility; and Jesica clearly had become—because of her body’s rejection of the first set of organs—extraordinarily ill. As ethicists and legal



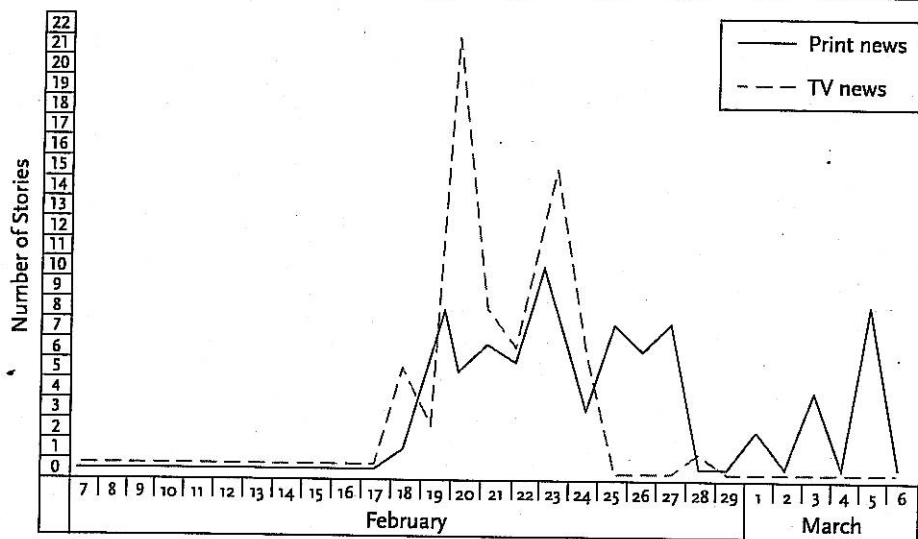


experts debated the wisdom of the "sickest first" allocation system and while others wondered why an illegal immigrant received a transplant in the first place, within days of the second transplant the story of Jessica Santillan was becoming more complex.

While, for some, Jessica became the face of an important issue—the short-



age of organs for children—she was also described as an unfortunate example of the toll of errors in cutting-edge medicine. But in the wake of the second transplant, her case would also become a potent immigration narrative. The media embraced Jesica through the well-trod narrative of immigrants chasing after the hope of a better life in America. A great deal of action—both real



and symbolic—occurred around Jessica, and yet, because of the nature of her condition, she actually said and did the least in these news accounts. The lack of reportable action, then, left readers dependent on the various media attributions to link particular motives, sentiments, and feelings to Jessica. Where other characters might be allowed to speak for themselves, these actors in the drama (and the writers of the various news accounts) also spoke for Jessica in the unfolding media coverage.

Initially, accounts described Jessica in various and often conflicted ways. Some saw her as a seventeen-year-old, desperately ill patient with a grave prognosis. Others characterized her as a “botched transplant victim,” and drew attention to her status as a poor, small-town girl. Elsewhere, Jessica was referred to as a “baby [that] needed some help,” echoing her mother’s characterizations, and some media stories further embellished her profile as the “world’s sweetheart.”<sup>6</sup> As Nancy King and Carolyn Rouse point out elsewhere in this volume, the media was drawn to her as a “mediagenic” individual—and these accounts quickly cast her as a young, pretty, “innocent,” and sympathetic figure. The combination generally evoked positive public reactions.

At the same time, however, news stories rarely failed to mention her immigration status—albeit in various ways. Jessica was described as a “Mexican teenager,” a characterization that eventually morphed into “Mexican im-

grant from Mexico." The transformation in terminology reveals much about the shifting public meaning of the case. The "illegal immigrant" characterization invigorated controversy, for it shifted attention away from error and Jessica's victimization to her impropriety—put bluntly, to the question of whether an illegal immigrant should be allowed to receive transplants in the United States. As Beatrix Hoffman and Leo Chavez note elsewhere in this volume, long-standing concerns about immigrants' rights to health care shaped these public reactions to Jessica's case. And as we see in Jed Gross's essay, these anxieties could also emerge around cases of wealthy foreigners purchasing access to transplants in America. In such cases, immigration anxieties often commingled with barely submerged public mistrust about the allocation system.

Media claims of public outrage over Jessica's transplants peaked after her death, and a great deal of animus centered on claims of theft—or (as articulated by one college newspaper) that Jessica "[came] into our country and [took] the organs of not one, but two people, that could have gone to more deserving Americans."<sup>7</sup> By late February into early March, the tone of coverage had become inverted in crucial ways. When, early on after the first transplant, the outlook for Jessica had been most grim, stories cast her as an innocent victim; yet, just when events took a positive turn and Jessica received matched organs, questions of privilege and special consideration emerged. As her condition changed yet again and as her health declined, these conflicted characterizations would continue.

The often hyperbolic images of Jessica in the amalgam of news coverage traversed a spectrum between thieving immigrant and martyred saint. In the most vitriolic description, a caller to a radio show in the Southwest labeled her as a "wetback" immigrant who took organs from dying Americans.<sup>8</sup> On CNN, on the other hand, she was called "America's sweetheart" who had touched the hearts of many.<sup>9</sup> These images, of course, had little to do with Jessica herself, and much to do with popular American, even mythic, representations: the innocent victim, the underdog fighting the heartless system, on the one hand; and, on the other, the despised lawless outsider using precious resources intended for others, her greed resulting in the death of others.

#### PORTRAYING THE SANTILLAN FAMILY

In many respects, it was Jessica's family who bore the brunt of this characterization as conniving thieves (as we shall see later), but they themselves also

coverage saw the family's first appearance. The Santillan family spoke little English. Through a translator, they called the mistake "unforgivable," but Jessica's mother and father remained focused on obtaining a new transplant.<sup>10</sup> Their grief was evident but so too were the spontaneous bouts of anger toward the doctors and hospital. For example, when they called Duke Medical Center "piranhas," they evoked predatory and even vampiric images that had long circulated in social representations of organ donation and transplantation. The family's pronouncements in the media captured much about the public's sentiments about medicine and error. Magdalena Santillan, Jessica's mother, was reported stating bluntly that the "doctor should go to jail," and yet other stories showed her pleading for anyone concerned or anyone with a dying child whose organs might be available to help her find "the organs that my daughter needs to live."<sup>11</sup>

The Santillan family's direct appeal for public support and organs to save Jessica would have lasting implications. It foregrounded into public view another notion that had long been associated with transplantation: that public pressure, backroom deals, and the special status of patients were crucial factors in determining who received organ transplants. When Jessica received the second transplant days later, her mother's expression of gratitude to both the donor family and the media reinforced these sentiments. Magdalena suggested (and one CNN story translated her words) that "if it hadn't been for the support from . . . TV, from radios and newspapers . . . they would have let my baby die. I've seen a lot of cases where they don't pay much attention to Latinos."<sup>12</sup> But at the same time, Magdalena was also reported to have said that doctors had now done all they could.<sup>13</sup> And in the days after the second transplant, as Jessica's health began to deteriorate, the Santillan family receded from most news accounts.

But throughout the ordeal, the family's voices were often complemented by other actors who spoke for them. As the news commentary expanded, indeed more and more figures became involved in representing the family. There was, for example, the ever-present Mack Mahoney, and Renee McCormick (a spokesperson for Jessica's Hope Chest, which had been created to raise funds to pay for her transplant). Various reporters and television anchors also spoke for her family in a distant way, and even the Mexican consulate would represent the family's position at one point. Media coverage made continual references to the fact that the family relied heavily on translators and intermediaries to communicate with doctors, the hospital, and the public. The Santillans, in this view, were severely limited in their capacity to help

quently mentioned theme in news stories) reinforced the family's immigrant status. Early on, news stories reported, the family had granted power of attorney over Jessica's health care to Mack Mahoney. Mahoney himself, commenting on his role and their linguistic vulnerability, noted to a North Carolina journalist: "Nobody else can fight for her. Her family does not speak English. [The hospital] can bully them around and do all they want to, and I just refuse to let them bully me."<sup>14</sup> Such widely reported sentiments fostered an image of family dependency, need, and helplessness that would remain vital to the public story. Jessica's parents needed assistance in caring for their daughter. Media accounts portrayed them as adrift, confused, weak, easily influenced, and powerfully dependent on and beholden to patrons like Mahoney, and (by extension) to American goodwill writ large. That the family "only spoke Spanish" and relied on a translator constantly reminded readers and listeners that the Santillans were not Americans. Throughout the tragic story, as more and more of these intermediaries took center stage, it would become increasingly difficult for readers and listeners to discern whether the family had expressed particular ideas and sentiments, whether they originated with the friends or spokespeople, or whether they were merely free-floating, media-generated sketches presented as the family's attributes.

#### **MACK MAHONEY AS RENEGADE COWBOY**

It was not the family but Mack Mahoney who played the central protagonist in media accounts. Mahoney facilitated much of the action that was documented in news coverage. As the news later reported, it was Mahoney (after he first learned about Jessica's plight from a local North Carolina newspaper) who attempted to make an anonymous donation to the family in order to help her obtain her first transplant. When the family insisted on meeting him, an unusual relationship blossomed. In early accounts, then, Mahoney's closeness to the family came sharply into view; and stories characterized him as Jessica's "benefactor" and as the founder of Jessica's Hope Chest, a foundation to help critically ill children. Mahoney asserted himself with journalists as a credible family spokesperson, recounting the daily turmoil surrounding the transplant error and describing its impact on the Santillan family. Television coverage showed him criticizing the hospital for not admitting their mistake in public soon enough, and he was one of the prominent public faces in the family's appeal for a directed donation. Mahoney characterized himself as an irreverent cowboy of sorts, a Dallas native who seized the reins and took



news accounts clearly found this image appealing and developed it fully in their profiles of Mahoney. One report in a Charlotte, North Carolina, newspaper noted, for example, that "Mahoney says if the hospital had gone public with the mistake immediately after the surgery, there might have been a better chance of finding a new donor."<sup>15</sup> In contrast to the hospital, which was criticized for allegedly delaying and dissembling, Mahoney was portrayed as blunt-spoken and ready to take action: "[W]e're gonna get everybody together and we're gonna find that baby some organs," he said on CNN on February 20.<sup>16</sup>

Such stories presented Mahoney as a man of action. Mahoney "took on the hospital," noted one account, drawing attention to the claim that he would not be bullied. Through the media, he issued stark challenges to the hospital's administrators, insisting at one point that "if she dies, Duke will have murdered her," and (later, as death neared) that "[the hospital] let my baby lay on that bed . . . and she's probably going to have brain damage, and, you know, guess whose fault that gets to be?"<sup>17</sup> Other stories reported that it was Mahoney who had pushed the family to go public with their appeal. And most accounts saw him as a positive if belligerent force in the story, "battling" with Duke as the hospital sought to avoid the bad publicity. As CNN put it, "Knowing that the time was running out for the girl [Mahoney] calls 'the world's sweetheart,' Mahoney sprang into action to get the word out to the media that Jessica needed a matching donor."<sup>18</sup> In some accounts, Mahoney's benevolent aggressiveness was even credited for getting Jessica the first transplant—and here, again, one sees the ways in which public ambivalence about organ allocation would be fostered. Other stories, however, such as the *New York Times's* portrait of him as "a hand grenade in a china shop," offered less generous representations of Mahoney.<sup>19</sup> At times depicted as aggressive and benevolent, but also destructive, Mahoney was nevertheless portrayed as a necessary catalyst for action that could have saved Jessica's life.

After Jessica's death on February 23, Mahoney receded from the glare of the public spotlight with the simple statement: "I'm done. There's nothing more to say."<sup>20</sup> In the wake of his silence came a new type of coverage reassessing his role and sketching a less flattering profile of the man. Reflective essays and news analyses now described him as a "displaced Texan," as a "bearded 55-year-old with a white Panama hat and a raspy Texas accent," pointing more forcefully to his own uprooting and displacement.<sup>21</sup> Other accounts delved deeper into his own past, noting, for example (as one article did on the eve of Jessica's death), that he had lost his own son to medical error twenty years

...gave new significance to Mahoney's advocacy, his creation of a foundation in Jessica's honor, his role in applying for work visas for the Santillan family, and his fund-raising for Jessica's medical expenses. This notion of a hidden past evokes, of course, images of a lone ranger, championing the cause of the helpless, tired, and weary, taking on the powerful and pushing up to and sometimes beyond the limits of the law in service of a worthy cause. Such media stories, then, likened the Texan Mahoney to an iconic American character: the cowboy. His abrupt departure from the public eye after Jessica's death further reinforced this lone ranger image. His cowboy story, however, did not end happily. The image fostered ambivalence. And it is not altogether surprising that even while Mahoney could be characterized as a lone ranger, so too could Dr. Jagers be figured as a renegade cowboy surgeon (as Nancy King and Carolyn Rouse note in their essays in this volume). Perhaps, in the media's perspective, it took one cowboy to effectively confront another.

#### IMAGERY AND INSTITUTIONS: DUKE UNIVERSITY HOSPITAL

Throughout the coverage of the Santillan case, competing representations of Duke Hospital vied with one another. Many accounts represented Duke as "one of the world's leading centers for organ transplantation" and as a medical institution involved in groundbreaking work.<sup>23</sup> The hospital was "well-known" and "renowned," making it all the more striking (in the media's perspective) that crucial safeguards had failed. From the outset, the focus rested on failing safeguards rather than on negligence per se. An "elite" medical institution, Duke appeared to be part of a large systemwide error, and thus the event was seen as a "grim reminder of what can go wrong even with top-rated surgeons at a first-rate hospital."<sup>24</sup>

But Mahoney and the Santillan family promoted a different characterization of Duke: an institution that was "very hard to deal with," one that failed Jessica once with the egregious error and a second time by not being forthcoming with the family and with the public.<sup>25</sup> Against this backdrop of elite medicine, error, and blame, Duke was presented on *CBS News* and in other outlets as "image conscious" and "insensitive," as "piranhas," or as bureaucrats who "dragged their feet" or who were most concerned with public relations and "wip[ing] the tarnish off their image." Expertise gone awry and arrogance was a major theme in some of these published stories. At one point, Mahoney bluntly asserted, "Duke is as arrogant as hell is hot."<sup>26</sup>

At the center of these widely varying and heated representations of the

responsible for the error, for the declining health and the death of the young Jessica? The question of culpability hung in the air around press conferences and in media stories, drawing attention to the inherent defensiveness of Duke's pronouncements. As media coverage of the case began, for example, administrators referred to the mistake as a "tragic error" even as they publicly accepted responsibility. Dr. Fulkerson, chief executive officer of the hospital, assured the family and the public that "[the hospital's] focus is really on her care here. And we have an extraordinary team of people that are working very hard to try and stabilize her."<sup>27</sup> In the context of heated accusations and the extraordinary error, Duke's apology could be read in different ways: was it admirable forthrightness under difficult circumstances? Or were their words read as superficial and unsatisfying attempts to shape future discussions about the institution's liability?

While the second transplant operation quieted the Santillan family's public condemnation of Duke, it opened another contentious line of public criticism, coming from new sources and focusing on whether or not the hospital should have attempted the second operation, on the motives of the hospital in working to secure a second set of organs, and on whether any extraordinary measures were taken to obtain these organs. By the time of the second transplant, the consensual reality of the case as represented in media stories held that Jessica's chances of survival were slim and declining. Duke's administrators remained optimistic in their public statements, asserting that her chances of surviving were 50-50. Other physicians and ethicists who were called into the public commentary disagreed, and another round of critical commentary on CNN, CBS, and other sources focused on the possibility that the hospital was wasting "scarce resources" and doing so only in a desperate effort to "fix their mistake."<sup>28</sup> (This topic—the second transplant and the debate over futility—is discussed at length in the essay by Wailoo and Livingston.) Without question, the second transplant served as a turning point in media coverage, for now much of the media commentary on Duke was centered on the fairness and wisdom of the second operation, and not exclusively on the original error.

Further controversy flared when Duke physicians declared Jessica (declining fast after the second operation) to be brain dead and pushed for removing her from life support despite her family's apparent resistance. Here was yet another conflicted image of the institution appearing toward the end of Jessica's life, and media attention swung to cover the acrimony and misunderstanding over the question of whether Jessica was dead. Bioethicists commented that Duke's actions (in this instance) were not only defensible but

representations of the high-tech institution, its motives, behaviors, and pronouncements, and the fate of patients within its doors. If the beginning of the public story cast Duke's high-technology facility in ambivalent terms (as both a mecca of modern medicine and as a site for unconscionable mistakes), then the concluding story about removing "life support" suggested another ambivalence about public concerns about premature declaration of death in service of organ donation. Duke hospital, throughout the Santillan drama, remained part of a complex array of stories touching on institutional and medical mistrust, on malpractice and institutional sensitivity, on error and its origins, and on the place of organ donation and transplantation in modern medicine and society.

### **JAMES JAGGERS: CONFLICTED PORTRAITS OF A DUKE SURGEON**

When the error was discovered, Dr. James Jagers—the surgeon who led the first transplant team and who had unwittingly transplanted the mismatched organs—was portrayed as forthright with the family. By all accounts, Jagers took direct responsibility for the mistake, even as Duke's administrators suggested that a "clerical error" was responsible. Some stories delved deeper into the sequence of events, however, suggesting that Jagers had failed to request information about the blood type of the donated organs and had failed to reconcile the organs' blood type with Jessica's. With one glaring exception, neither the family nor the media attacked or criticized Jagers on a personal level. *Newsweek* later presented Jagers as having the "courage to go out and tell the truth."<sup>29</sup> His remorse for the mistake earned much media attention. As the story broke, for example, the *New York Times* offered these quotes: Jagers was "heartbroken about what happened to Jessica"; his "focus has been on providing her with the heart and lungs she needs so she could lead a normal life."<sup>30</sup> There was one stark exception to this trend, for initially the Santillan family had insisted that Jagers be jailed for the error; but then they quickly acknowledged that he had done everything possible for Jessica, and they professed their complete faith in his ability as a surgeon. As news accounts later reported, they even insisted that Jagers perform the second transplant surgery (although he was to be monitored). This tension over Dr. Jagers—who he was, what his commitments were, what level of responsibility he would take, whether he was an exemplary surgeon or careless practitioner—dominated the media coverage throughout the public life of the case.

the donated organs as a system error—thus shifting the focus away from the individual to the system and its multiple players and safeguards. Stories reported that the hospital and UNOS would conduct investigations to review the conversations and decisions leading to the error, but they insisted that such investigations would focus more on corrective action than individual punishment. Accordingly, most coverage cited Jagers's decisions as contributing factors rather than the primary error. As one *Washington Post* article stated, "Most mistakes are not the result of incompetent or uncommitted doctors, nurses, or pharmacists . . . they are rather, the result of a failure in the system."<sup>31</sup> Yet, in such accounts, the line between individual fault and system error was not always clear. Another story on CBS concluded, "Dr. Jagers never made any verbal confirmation that the organs were a match—a major oversight in the process."<sup>32</sup> In general, media accounts spread responsibility for the error to the large, complex, and diffuse administrative processes. These stories, therefore, relieved Jagers of personal culpability, even as at the same time (ironically) he freely accepted responsibility. It is unclear to what extent his initial public display of remorse and his overt acceptance of accountability influenced the tenor of subsequent media coverage, allowing writers and commentators to grant him a kind of preemptory reprieve. (For more on this topic of individual and systems error, see the essay by Charles Bosk.)

Certainly, his status as a respected surgeon at an elite medical center, as well as the heated rhetoric surrounding Duke more generally, would have contributed to these media representations of the doctor. Stories were quick to point out that Jagers was well-respected in the medical community. As one account on MSNBC noted, "From all accounts, Dr. James Jagers is an exemplary surgeon . . . no one will say a negative word about him. He is apparently a very caring, compassionate person, and a family spokesperson says he wept after telling the family that he had made that tragic mistake."<sup>33</sup> This image of a exemplary practitioner, a compassionate man who was also capable of weeping at the bedside preemptively redeemed Jagers in many media accounts. Another early report, for example, stressed that Jagers "volunteered to go to Nicaragua to perform heart surgery on underprivileged children in that area. . . . [He was] known as the go-to guy here when dealing with babies with heart problems."<sup>34</sup> Such accounts of the surgeon's admirable character, found frequently in the coverage, insulated him from much of the public blame. Jagers, however, did not escape blame everywhere. Some stories called for his resignation. Others noted that while he would be formally reprimanded, it was ironic that his work would continue: "Jagers will

somewhere, there needs to be some sort of punishment. . . . A child died on his watch, and it was his fault because he did not double-check the blood type with that of the recipient."<sup>35</sup> In this telling, Jagers was a reckless and powerful surgeon who would go unpunished for his extraordinary and deadly mistake. Yet such angry portraits were overwhelmed in numbers by positive and sympathetic images of Jagers. One *Washington Post* editorial put the ambivalence toward Jagers this way: "He's become a figure both noble and detestable, the captain of a sunk ship, a confirmation that Americans mythologize doctors while deeply suspecting them of the capacity for great arrogance and harm."<sup>36</sup>

Ambivalence pervaded media representations of the main characters in the Santillan story, but the media coverage of Jagers was particularly fascinating, for it reinforced a particular mythology (that the doctors were compassionate and noble in their efforts to help patients) while also drawing attention to a competing set of notions—that they were not entirely trustworthy and often remained above normal systems of accountability.

#### **BUREAUCRACY AND BARGAINING:**

##### **PICTURING THE ORGAN ALLOCATION SYSTEM**

If tension and ambivalence characterized coverage of Jagers and Duke, then how did the organ allocation system fare in these media accounts? The case did provoke the media to explain key features of the complex U.S. organ allocation system, but media accounts also fostered many new concerns and anxieties about organ donation, allocation, and transplantation. At first, investigative news coverage sought to determine just how and where the mistake could have happened, and this involved detailed explorations of the blood-type matching and the role of organizations like UNOS in shaping the fateful error. After Jessica's second transplant, however, these examinations shifted to the broader-based ethical questions about how hospitals and UNOS determined eligibility of citizens and noncitizens, and about what criteria determined how patients rose to the top of the transplant queue. Reporters, commentators, medical ethicists, letter writers, and others raised questions of fairness in the wake of the second transplant—and media investigations of the transplant system took on a broader set of meanings. Was it fair, several stories asked, to give an individual like Jessica not one but two sets of new organs? The question provoked many to speculate that factors beyond clinical need influenced allocation, not just in this case, but more generally.



timing of the medical error, and about the character of the transplant system. All acknowledged that the process had broken down—but where and when? Some stories suggested broadly that “the system” was to blame; a few others highlighted UNOS’s role (rather than Duke’s) in attempts to discover where the miscommunication had occurred. Initially, such stories highlighted the slim likelihood that Jessica would be able to obtain a second set of organs; for example, one CNN story quoted a UNOS spokesperson’s view that it would be an “uphill battle” because of the national shortage of donors.<sup>37</sup> Yet, because Jessica was now listed apparently as a “medical necessity,” this designation ensured that her chances were quite good. Regardless of her designation, UNOS was compelled to explain that the rules of organ allocation prevented them from specifically searching for organs for Jessica. This was, they pointed out, simply not how the allocation system worked. (For more on this discussion, see the following essay by Richard Cook.) Clearly, however, Mack Mahoney and the Santillan family strongly believed that public pressure, media attention, and special pleading would be a factor in obtaining a second transplant. News accounts seldom questioned this notion; nor did they point out that the publicity could, indeed, have stimulated a potential parent from making a directed donation if their child was dying—thereby bypassing UNOS rules.<sup>38</sup> Directed donation was at the time, and still is today, a heatedly debated ethical issue in transplantation, yet this dimension of how organs are allocated remained invisible in public commentary. The silence around the difference between directed donation, standard UNOS allocation, and issues such as medical necessity was a missed opportunity in media coverage. Instead, the media’s coverage spiralled off to investigate other hot-button ethical issues in organ donation.

Once Jessica received the second transplant (not through directed donation but through UNOS because she was listed as a “medical necessity”), commentary, speculation, and analysis dramatically shifted to the question of fairness. The organ allocation system was described as “complicated, often confusing, and certainly a highly controversial process.”<sup>39</sup> To many, Jessica’s receipt of two sets of organs and (despite this) her subsequent death “underscored a debate in medicine about the ethics of risky second-transplant operations at a time of grave shortages of human organs.”<sup>40</sup> A range of new voices unconnected with the specifics of the case entered these stories. Reporters began turning to medical ethicists, who referred to the new situation as “an ethical dilemma with few precedents.”<sup>41</sup> At the same time, the public commentary took many new forms as news writers also turned for commentary to people

the case. One MSNBC story, for example, speculated that people on organ transplant waiting lists might be perplexed, "sitting back and saying how come she got those organs so quickly."<sup>42</sup> *Newsweek* quoted a twenty-eight-year-old woman, a diminutive woman waiting for a heart-lung transplant, who suggested that "that could have been me [who could have received the transplant]."<sup>43</sup> The second transplant, then, led to a dramatic and qualitatively important expansion in the actors featured in the media coverage, many of whom led the charge in speculating about the motives of the main actors and many of whom positioned Jessica at the center of their own questions about the fairness of the allocation process and their own life-and-death chances. (Again, see the essay by Wiloo and Livingston for more discussion of this theme.) The ethics debate could turn heated at times. While one ethicist argued in the North Carolina-based *Charlotte Observer* that Jessica truly deserved the second transplant because she "never really got the first transplant" (because of the incompatibility of the organs), another on MSNBC pointed to the other silent actors off stage, insisting that "there are kids in the United States waiting for these organs and I don't [think] giving them to the person with the longest odds makes sense."<sup>44</sup>

Such outside commentators were among those leading the discussion about whether Jessica had received special privileges, and whether doctors manipulated the system in order to "fix their mistake." A few early reports had raised the possibility that Duke doctors had "pushed all the connections they had—not because of their mistake . . . but because Ms. Santillan's condition was so dire."<sup>45</sup> However, a growing number of sources developed this theme. One ethicist described it as a "horrible moral tension" in which doctors now perceived a special obligation to act because they made a mistake.<sup>46</sup> The perception of special manipulation on Jessica's behalf was only accentuated when, later in the year, other transplant scandals drew attention to the "impromptu bargaining" that occurred occasionally when a patient is not on UNOS's match-run list.<sup>47</sup> (Richard Cook's essay provides a detailed description of this issue of "bargaining," a term that carries a meaning in the context of allocation that differs somewhat from the public understanding of bargaining.) In the media, "bargaining" for organs could take on the appearance of a suspect and nefarious practice. Bargaining, as Cook makes clear, is a common part of the process of determining the clinical and biological fit between organ and potential recipient, even though it is discouraged by UNOS, which created the match-run list system precisely in order to prevent doctors from "gaming organs."<sup>48</sup> Other accounts went further, suggesting that doctors

mistake with a new set of organs that matched her blood type.”<sup>49</sup> Such depictions of the character of organ allocation unquestionably fostered mistrust not only of doctors and the hospital but also of the other actors in the process, and inextricably linked the Santillan story and Duke’s doctors to ethical dilemmas that underlie the allocation process.

While ethicists, doctors, and would-be recipients questioned whether Jessica should have received a second set of organs, others used the opening to question whether she should have received even the first set. Late in the media coverage, as Jessica’s condition declined, another debate ensued over whether immigrants should receive expensive organ transplants. UNOS publicly defended their standard practice, noting that immigrants like Jessica were indeed eligible for transplantation, and that a specific percentage of organs (5 percent) were allocated to immigrants. Moreover, UNOS insisted that immigrants in America actually donated *more* organs than they received. Investigative reports, however, pointed out that there were many conflicts within UNOS on the question of transplants for immigrants, nonresidents, and undocumented immigrants. As MSNBC reported, according to UNOS’s definition, an eligible nonresident was an immigrant who is in the country legally. Jessica Santillan, of course, could not be considered to be eligible. However, media coverage made it clear that UNOS and hospitals rarely, if ever, adhered to this definition for practical reasons. As a UNOS representative noted, “We do not differentiate between whether a transplant patient has legal or illegal immigration status.”<sup>50</sup> And a Duke hospital representative framed this decision in broader terms when he stated that “the duty of the hospital is to provide healthcare to all people, regardless of immigration status.”<sup>51</sup> Such statements drew further attention to the role of such key players as UNOS—if not in the error itself, then in the decision to transplant. Reports on organ allocation policy highlighted how the shifting public discussion was coming to rest on questions of fairness and justice in transplantation. Organ allocation was truly a complicated process that the public and the media grasped imperfectly. It proved far easier to focus on cowboy surgeons, outspoken benefactors, troubled institutions, and illegal immigration (which became, by the end of the story, the dominant theme in the media commentary).

#### THE PUBLICIZED IMAGE OF IMMIGRANTS IN AMERICA

The topic of immigration served as a critical backdrop for most of the coverage regarding the Santillan case. Not only did the focus on immigration

fueled the ethical argument regarding the allocation system.

Immigration aside, the narrative of the Santillan family resonated strongly in the American consciousness: a desperate family leaving everything behind, going to great lengths to get their daughter the medical care she needs to live. However, in the media coverage of the Santillan family a remarkable shift occurred as the story unfolded—a shift from portraying the family as heroes to portraying them as thieves. Initially, the Santillans' immigration status was a sympathetic framework for the media coverage of Jessica's dire condition and her need for advanced medical care. Monica Quiroc, an immigrant from Peru, was quoted in the *New York Times*, "They came for the reason why all of us come, because things are better here, or at least, they're supposed to be."<sup>52</sup> The *Washington Post* echoed this theme: "Jessica needed the transplant because a heart deformity kept her lungs from getting her blood. Her parents paid an immigrant smuggler to get the family into the United States from Mexico three years ago, in part for the better odds of landing a transplant for Jessica."<sup>53</sup> The Santillan family's experience was, in this telling, an epic journey of hope for a better life. The *New York Times* coverage, for example, described the Santillans as having "been on an odyssey to save their daughter's life that has taken them from the shacks of Guadalajara to the self-proclaimed City of Medicine."<sup>54</sup>

After her death, however, the description of their "odyssey" began to change to include other features of their immigration story—for example, that they "raised \$5000 for a 'coyote' to smuggle them in."<sup>55</sup> Such details reinforced the view that the Santillans' immigration experience was a heroic journey that also involved sly and dishonest smuggling. The Santillan family's desperate journey of hope was also an act of criminal trespass. One account, notably from the Southwest, even portrayed the family as having "dared" to come into this country to take a heart-lung set away from others who may have died while waiting for transplants.<sup>56</sup> These accounts exploited stereotypical images of immigration—catering specifically to American fears of immigrants.

Retrospective accounts of the case continued to play upon the more negative or ambivalent immigrant stereotypes, offering images of a family who "stood on street corners with tin cans to collect money for their sick child."<sup>57</sup> Such images of solicitation and poverty were enriched by other descriptions of the Santillan family as "poor laborers" and portrayals highlighting that "the family of five was living in a relative's trailer parked near the cucumber shed where farmers brought their produce to sell to a pickle company."<sup>58</sup> Not

large Spanish-speaking community of "Mexican immigrants." Their reliance on others to accommodate their English language deficiency could further the belief that the Santillans were not interested in assimilation, even as (as some suggested) they simultaneously exploited the best that America had to offer. Images of the Santillans' "abuse" of the system, their opportunism, and their alleged exploitation of America itself continued even after Jessica's death, as coverage focused on the Santillan family's desire to bury Jessica in Mexico and their unwillingness to leave the country if it meant being barred from returning to America.

The constant discussion of the Santillans' immigrant status and the methods by which they smuggled Jessica into the United States conjured up images of the racialized foreigner sapping American resources. Ultimately, Jessica was portrayed as an illegal immigrant who robbed more deserving Americans of a new chance at life. To make matters worse, many stories suggested, not only were two sets of organs made available to Jessica, but, with her death, she herself did not become an organ donor. Whether the family was told that Jessica's organs were not viable for transplantation or whether the family *chose* to refuse to donate her organs was not entirely clear from the media coverage.<sup>59</sup> Nevertheless, it was said that, in the end, she deprived others of the chance she had been given. As Mahoney commented to one journalist on February 23, "We have received several scathing e-mails from people who are concerned that the family refused to donate Jessica's organs." He noted, however, that her body was "so saturated by medications and anti-rejection drugs" that most of her organs were not reusable.<sup>60</sup> Despite such assurances, however, by the end of the saga, the powerful allegations of their refusal to donate were left hanging, unproven and mostly unchallenged, in public accounts. Ultimately, the image that the American media dwelled upon was of the Santillans utilizing America's "precious resources" and not giving anything in return.

Through these shifting portrayals in the media, the Santillan family became both respected and detested, the subject of contentious media image-making reflecting two sides of the coin that is "the American dream." On one hand, they represented the belief that individuals could "make something of themselves" if only they worked hard enough. On the other hand, in trying to fulfill the American dream, they allegedly stood in the way of Americans who also wished to fulfill similar dreams; they robbed other American transplant patients, it was said, of the "dream of a chance at life." These themes of legiti-

American media enjoys a remarkably ambivalent relationship with organ donation and transplantation. While coverage in the news often presents a mixed picture of organ donation, very much like the one that appeared in the Santillan story, depictions of organ donation in the entertainment media tend to be even more problematic and negatively focused on scandal. Story lines in major motion pictures like the film *Blood Work* (2002), starring Clint Eastwood, or daytime dramas such as *One Life to Live* (May 2004) perpetuate many of the myths and fears about organ donation. In *Blood Work*, for example, a murderer targets people with specific blood and tissue types in an effort to obtain organs for a particular person on the waiting list. Other popular films in recent years revolve around similarly macabre story lines, like the one in which organ recipients take on the characteristics of their donors or another about the black market trade of organs in the United States.

As damaging as many fictional portrayals are, and as ambivalent as "normal" news coverage is, neither has as much potential for shaping attitudes and beliefs about organ donation as the real stories that stem from medical events or that contain as much hope, tragedy, and horror as the Jessica Santillan case did. The story would have been compelling and damning enough if it were covered as the story of a young American girl who suffered such a tragedy as the result of a medical mistake. That story line alone would have captured many of the current fears about organ donation and fed into broader issues of mistrust of the medical profession, fairness in allocation, and misunderstanding surrounding issues like brain death. But when this story line became intertwined with even more hotly controversial issues like illegal immigration, the potential for negative impact on ideas about organ donation was even greater.

The Jessica Santillan story contained all of the elements necessary to foster public ambivalence and trigger the development of conflicted social representations about organ donation in the American media. There was the controversial Mack Mahoney, the remorseful Jim Jagers, the elite but "difficult to deal with" Duke University Hospital administrators, and the beleaguered Santillan family. And there was, of course, Jessica. As a beautiful but gravely ill young woman, Jessica Santillan elicited sympathy when she was portrayed as the victim of a series of medical errors. However, as the fairness of organ allocation became a public issue, she was represented as a beneficiary of ill-



corruption in the organ allocation system and of a "brown menace" of undocumented immigrants taking advantage of America's advanced medicine, leaving taxpaying Americans stuck with the bill, and resulting in worthy recipients dying on the transplant waiting lists. It was a story that captured many of the fundamental contradictions and ambivalences that society cultivated on a regular basis with regard to not only organ donation but also immigration and the American dream. Americans are often drawn to news about medical miracles and new technological approaches that can save lives. However, they are also often horrified by the image of arrogant doctors "playing God" and building human bodies from other people's body parts. And while the media trumpets a widespread public belief that everyone has the right to the American dream, there is also attention to the public's reluctance to share that dream with the "less deserving."

The Jesica Santillan case and its diverse elements created an overarching narrative that captured public attention and focused it, in an unusual and sustained way, on important issues in organ donation. It is unfortunate that this narrative also exposed a sometimes ugly attitude in various part of the nation about both organ donation and immigrants. Tragic as the story was, though, it did offer opportunities for constructive dialogue and forward-looking coverage about organ donation, medical ethics, and the allocation system. UNOS did successfully use the tragedy to change and improve the system of checks and balances. However, many other opportunities were missed. Whether this is the fault of the news media for focusing on the tragic and dramatic side of the story, or the fault of Duke hospital administrators (constrained as they might have been by issues of confidentiality and liability) for not being more proactive and forthcoming in their position, or the fault of others in the field of organ donation for not engaging more aggressively to dispel many of the myths or false assumptions that were presented, the fact remains that the most compelling media images portrayed were of incompetence and unfairness in the allocation process.

What, in the end, can we learn from the way in which the Santillan drama played out in these media accounts? According to Serge Moscovici, the writer Frank Kermode once stated, "A great narrative . . . is the fusion of the scandalous with the miraculous."<sup>61</sup> If that is the case, the story of Jesica Santillan is a perfect example of "a great narrative," and this fact may explain the intense media coverage. Few events could be portrayed as more miraculous than a heart transplant saving the life of the little girl, yet few events could have been more tragic or scandalous than her death and the charges that

their hands—were responsible for her death. The real challenge that lies ahead is sorting through these media images to unpack and analyze them more thoroughly, and to dispel the intensely negative social representations of organ donation that are generated from frequently sensationalized media coverage.

## NOTES

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Systematic thematic analyses of all actors in this case revealed themes for each actor that were consistent with coded categories, but as key events occurred, coverage

for instance, doctors may be framed as heroes and/or villains, common themes in organ donation stories. These shifts in framing were analyzed and linked to the timeline for the case and then cross-analyzed against broader categories such as immigration or ethical issues for organ donation as covered in all stories. This method provided not only systematic stories and representations of key actors but also wholistic pictures of key issues surrounding organ donation in relation to this specific case.

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