

## **“Team Sarah”: How a Small Group of Public Relations Volunteers Helped a 10-Year-Old Get New Lungs and Changed U.S. Transplant Policy**

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### **Abstract**

When 10-year-old Sarah Murnaghan was in dire need of a lung transplant, a small team of public relations practitioners volunteered to help make it happen. “Team Sarah,” as the professionals became known, quickly implemented a zero-budget, pro bono campaign that integrated media outreach, social media activity, and government relations. The team generated extensive media coverage and social media attention and prompted several political officials to advocate for Sarah. These efforts not only raised the visibility of Sarah’s case and helped her get donor lungs in only three weeks, but also changed U.S. transplant policy. Because this was the first time a comprehensive and professional strategic communication campaign had been used to aid a patient awaiting a transplant, the impact of Team Sarah’s efforts has sparked both praise and criticism.

**Keywords:** Team Sarah; Sarah Murnaghan; lung transplant; transplant policy; strategic communication; public relations campaign; social media campaign; case study

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### **Introduction**

In spring 2013, Sarah Murnaghan, a 10-year-old Pennsylvania girl with cystic fibrosis, desperately needed a lung transplant. At the time, she was among the more than 121,000 Americans on the national waiting list for donor organs and one of 1,600 waiting for donated lungs (Organ Procurement and Transplantation Network, 2014). Some patients wait years for a transplant, and an average of 18 people die each day from the lack of available donor organs (“Statistics,” n.d.). Sarah had been on the waiting list for 18 months. As her condition worsened, she was hospitalized in February 2013 and placed on a ventilator.

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U.S. transplant policy specified that although children were first in line for donor lungs from children, they were last in line for adult lungs, which are donated far more often (Halpern, 2013). Sarah's parents, Janet and Fran Murnaghan, grew increasingly convinced of the unfairness of the policy and became determined to change it (McCullough, 2013a). Janet Murnaghan, a former television news producer and public relations practitioner, knew the power of public relations to raise the visibility of Sarah's case. On May 23, 2013, she posted this message on her Facebook page seeking help "to get this story on the national stage":

Dear friends from my former PR life,

Sarah needs your help. She has only a week or two before she will lose her battle with Cystic Fibrosis if she does not receive donor lungs. If Sarah was 12 years old, she would have a high probability of receiving lungs in time. Since she is 10, she will only receive adult donor lungs after all adult candidates, regardless of how sick they are, have the opportunity to accept donor lungs. We need to draw national attention to this arbitrary ruling which costs children their lives. I need your ideas and efforts to make this happen quickly.

Nine friends and former colleagues—all senior public relations professionals and mothers themselves—responded, and "Team Sarah" was born. Some knew Janet Murnaghan well from working with her at the Tierney Agency, a public relations and advertising firm in Philadelphia, but several knew her only slightly. "We all felt, 'What if this was me and my child?'" said team member Tracy Simon. Team Sarah's efforts to generate awareness of Sarah's case through extensive media outreach, a social media campaign, and government relations not only helped Sarah get new lungs, but also sparked national discourse about the fairness of U.S. transplant policy and ultimately helped change the policy. It was the first time a "PR blitz" of this magnitude had been used to aid a patient needing a transplant (Halpern, 2013), and the impact of the zero budget, pro bono campaign, which won the 2014 PRWeek award for Public Affairs Campaign of the Year, drew both praise and criticism.

How did Team Sarah rapidly plan and implement strategic communication for a case that became one of the year's most prominent medical stories—

a case that “tugged at the nation’s heartstrings” (Hellmich, 2013, p. 3A)—while also posing challenging ethical, legal, and political issues? How did they meet the needs of journalists hungry for details while protecting Sarah and her family and following the privacy rules of Sarah’s hospital? How did they quickly generate a groundswell of public and political support? What influenced their strategy and tactics? And what can be learned from their decisions and actions?

### **Background**

The first human organ transplant in the United States, a kidney transplant, occurred in 1954, followed by the first liver, lung, and heart transplants in the 1960s (Triant, 2012). But most early transplant patients did not survive long: the first lung transplant recipient lived only 18 days after surgery, for example (Koch, 2002). During the 1960s and 1970s, transplants were considered a rare, last ditch attempt to save a patient’s life (Koch, 2002). Recipient rejection was the biggest barrier to the growth of transplantation; because the human immune system is designed to repel foreign bodies, rejection of donated organs was common. Approval of the immunosuppressive drug cyclosporine in 1983 greatly reduced the rejection rate (Koch, 2002). Yet transplants are not a panacea: as of 2012, 83.4% of liver recipients were living five years after their transplant, compared to 76.8% of heart recipients and 74.3% of kidney recipients (“The Need,” n.d.).<sup>1</sup> Lung recipients have the lowest five-year survival rate: 55.2%. Nonetheless, more hospitals have established transplantation centers, making transplants possible for a greater number of patients. As demand for transplants escalated in the United States, the need for donors has increasingly outstripped supply (Munson, 2002). There are currently enough patients waiting for an organ to fill a large football stadium twice (“The Need,” n.d.; see Table 1).

The 1984 National Organ Transplantation Act established a national system to coordinate organ collection and distribution (Koch, 2002). The

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<sup>1</sup> Rates are for liver and kidney transplants from deceased donors. Five-year survival rates for patients who received organs from living donors are higher: 92.0% for kidneys and 81.3% for livers. All transplanted lungs and hearts come from deceased donors (“The Need,” n.d.).

**Table 1.** Supply and demand for U.S. organ donors.

Year	Number of Organ Donors	Number of Transplants	Number on Waiting List
1993	7,766	17,631	31,355
2003	13,285	25,473	83,731
2013	14,257	28,954	121,272

Source: U.S. Department of Health & Human Services ("The Need," n.d.).

U.S. Organ Procurement and Transplantation Network (OPTN) "helps ensure the success and efficiency of the transplant system" by managing the national transplant waiting list, matching donors to recipients, and "developing consensus-based policies and procedures for organ recovery, distribution (allocation), and transportation" ("The Need," n.d.). The United Network for Organ Sharing (UNOS) is a non-profit organization that runs OPTN for the Department of Health and Human Services (DHHS) ("About Us," 2014). Bioethicist Arthur L. Caplan of New York University Langone Medical Center asserts that although UNOS has occasionally sparked criticism and controversy, the system "has done a good job of distributing scarce organs without favoritism for decades." Sarah Murnaghan "put that system to its most severe test ever," he said (Caplan, 2013, p. 9).

Several months after Sarah entered Children's Hospital of Philadelphia (CHOP) in February 2013, Janet and Fran Murnaghan learned that an OPTN rule puts children under 12 on a separate waiting list for lungs than adults and adolescents 12-17 years old (Welch & Asher, 2013). While children under 12 have top priority for donor lungs from children and are second in line for adolescent lungs, they have the lowest priority for adult lungs (Halpern, 2013). That's because OPTN "says it lacks sufficient data on these transplants, such as procedures to pare adult lungs for children's chests" (Hollander, 2013, p. 9). But child lung donors are very rare: just ten lung transplants were done on patients in Sarah's age group in 2012 (Caplan, 2013). Sarah's parents believed the rule discriminated against children and should be overturned. They gave Team Sarah wide latitude based on personal trust, and the team's campaign not only drew

worldwide attention to Sarah's plight, but also encouraged the framing of the story in the most positive and sympathetic way possible.

### **Research**

Because of the hurried tone of Janet Murnaghan's Facebook plea, members of Team Sarah did not do any research themselves before first reaching out to the news media. Instead, team members were briefed by the Murnaghans, who had spent weeks researching the lung transplant rule and the organizations, agencies, and officials that governed transplant policy. "There was so much legwork that had already been done," Simon said. But after generating an initial wave of coverage about Sarah's case, Team Sarah took a step back and developed a five-page communication plan to ensure the consistency of the team's communications.

The communication plan included background on Sarah's situation, key messages, frequently asked questions, data, and analogies to explain lung transplant policy. The plan did not include a budget, because there were no funds, or a timeline, because Team Sarah intended to work as long as needed and develop as many tactics as necessary. The sole evaluation criterion was whether Sarah got new lungs. Key messages in the plan included:

- Ten-year-old Sarah Murnaghan is losing her battle with cystic fibrosis because of a policy that prohibits her from getting the adult lungs her transplant doctors have approved to save her life.
- Under current policy, if Sarah were 12 years old she would be considered equally among all others on this list for an adult lung transplant.
- Ironically, the system is intended to save lives by giving lungs to the most severely ill person first.
- The Murnaghans just want the system to work as it was set up to, allowing Sarah to be considered for adult lungs based on the severity of her disease.

- UNOS is reviewing these policies to make sure they are consistent with advancing medical technology. However, Sarah's case is dire and in order to treat her fairly, an immediate exception must be made first to extend her life.

Two team members introduced themselves to CHOP's public relations staff and reassured them that Team Sarah wanted to portray the hospital in a positive light. Team Sarah also developed several tools to streamline media outreach: a blank carbon copy (BCC) email list to send updates and pitches to scores of journalists with a single mouse click, and a Dropbox from which journalists could quickly and easily access written materials, photos, and videos. Internal team communication was managed through Facebook's instant messaging platform.

### **Strategy**

Team Sarah's campaign was shaped by three strategies. "The number one strategy was to put enough pressure on OPTN and UNOS to change their rule," said team member Maureen Garrity. Team members recognized that the officials and administrators who ran OPTN, UNOS, and DHHS, and the physicians who advised them on transplant policy, could be susceptible to political and public pressure to change lung transplant policy and not just make an exception for Sarah. The second strategy was to use a "surround-sound" approach to strategic communication: integrating news media outreach, social media activity, and government relations for maximum reach, longevity, and impact.

"We also needed to figure out how to humanize Sarah and her family," Garrity said. "We wanted the media to become emotionally invested in the story, not just cover it." Team Sarah implemented this strategy by describing the precariousness of Sarah's condition as well as her bravery and determination. Team Sarah also portrayed the Murnaghans as a close, loving family, and highlighted the fact that they had adopted a child from Ghana and were building a school there.

## Execution

### Raising Awareness

On the evening of May 23, 2013, the same day Janet Murnaghan posted her Facebook message seeking help, members of Team Sarah discussed what should be done first and then quickly wrote and emailed a pitch to their individual media contacts. It focused on the basics: the who, what, where, when, and how of Sarah's situation, including background on the lung transplant rule the Murnaghans were contesting. The pitch began: "I'm writing today with an extremely time sensitive and **TIMELY** human interest story idea for your consideration" (Simon, personal communication, 2014). For the Philadelphia media, the word "local" was added.

"It was a free-for-all that weekend," said team member Jill Monahan, adding that there was little concern about whether media outreach efforts overlapped. "We were all pitching like crazy." Team members said they were surprised at how quickly some news organizations responded because it was the start of Memorial Day weekend. "I was driving to the beach with my family and on the phone constantly with reporters," Simon said. "By the grace of God, it was a slow news weekend and a good opportunity for a good story to 'catch.'" CNN sent a crew to Philadelphia on May 24, 2013. "Within 24 hours we had secured a national story," Simon said.

CHOP does not permit journalists onsite, but the hospital allows parents of patients to take cell phone photos and videos of their children. So the CNN story began with the Murnaghans' video of Sarah, who was using a breathing tube, singing "Twinkle, Twinkle Little Star" while tapping out the notes on a toy xylophone (Welch & Asher, 2013; see Figure 1). CNN's interview with Janet and Fran Murnaghan, which took place at the nearby office of team member Denise Portner, was interwoven with a cell phone interview of Sarah, which struck a highly emotional chord: "I used to go to school before I got oxygen," Sarah said, wiping away tears (Welch & Asher, 2013, para. 13). "Got to go to school and at least try and act like all the normal children" (Welch & Asher, 2013, para. 13). Janet Murnaghan then criticized the transplant rule: "It shouldn't be about their age. If she's the sickest person, she should qualify" (Welch & Asher, 2013, para. 21). CNN



**Figure 1.** Sarah Murnaghan playing the xylophone in her hospital room. Source: Murnaghan family photo.

also interviewed Stuart Sweet, lung transplant director at St. Louis Children's Hospital and secretary of OPTN's board. He said that although Sarah's case "tugs at his heart," if the rule was changed to her advantage, "there's another patient, very likely an adolescent, who gets a disadvantage. We've built a system that tries to be as fair to everyone as possible" (Welch & Asher, 2013, para. 28-29). Social media conversation about Sarah increased eleven fold from May 26 to May 27 as the story aired multiple times on both days, according to monitoring data obtained by Team Sarah (Rachael Schwartz, personal communication, 2014).

The *Philadelphia Inquirer* ran its first story about Sarah on May 25, 2013, in response to the pitch from Team Sarah. The story noted that the Murnaghans had "launched a last-resort public-relations blitz" to change transplant rules so Sarah could be offered the first suitable lungs available, regardless of the donor's age (McCullough, 2013a, p. B1). "The law is, in my view, age discrimination," Janet Murnaghan was quoted as saying (McCullough, 2013a, p. B1). The *Inquirer* also interviewed Sweet, who noted that while the supply of pediatric donor lungs is small, so is



demand: “(Sarah) has virtually no competition in her age group. And you have to look at fairness from both sides. While children can use adult lungs, adults generally can’t use pediatric organs” (McCullough, 2013a, p. B1). The story was accompanied by a touching Murnaghan family photo of Sarah, who was wearing a ventilator, cuddling with her adopted sister from Ghana (see Figure 2).

### Expanding the Story

Although Team Sarah was pleased with the two stories, it hoped to generate more coverage of Sarah’s case. “National coverage on CNN validated the story,” Simon said. “If CNN covered it, it was real.” On May 28, 2013, Team Sarah distributed a news release via PR Newswire titled, “Murnaghan Family to OPTN/UNOS: Stop Age Discrimination! Change Policy to Allow ALL Approved Patients Under 12 to Receive New Lungs Based on Need.” It painted a vivid picture of Sarah’s condition to evoke sympathy:



**Figure 2.** Sarah (left) and her sister Ella cuddling in Sarah’s hospital bed. Source: Murnaghan family photo.

Each cough sends pains through her spine, with two fractured vertebrae from disease-caused bone break down. She has hearing loss in both ears due to toxic antibiotics necessary to save her life. She vomits daily, is fed through an IV and is strapped to masks that make communication even harder. She has CF-related diabetes and is pricked all day. Sarah has lost her childhood, her ability to live at home, and go to school. (“Murnaghan Family,” 2013, para. 5)

The release also included a quote from Janet Murnaghan that established the positioning that would be echoed in all subsequent communication materials from Team Sarah:

We are not asking for preference for Sarah, we are asking for equality...We strongly believe Sarah should be triaged based on the severity of her illness, not her age...If you took your child to the ER and they had to wait behind all the adult patients, regardless of the severity of their illness or when they arrived, wouldn't it seem like adults were being prioritized over children? That's what's happening here, and as a result, we're in a race against time to ensure that Sarah is treated fairly. (“Murnaghan Family,” 2013, para. 6)

That perspective was widely reflected in the resulting stories. For example, the Associated Press quoted Janet Murnaghan as saying, “We don’t want preferential treatment for Sarah, we want equal treatment. We want it to be a triage system like they do for everyone else where the sickest patient goes first and ones with ability to wait, wait” (Todt, 2013a, para. 5).

### **Marshaling Social Media**

Garrity posted an online petition on the Change.org website on May 31, 2013, to allow transplants of adult donor lungs to children. The petition was designed to engage and educate the public about transplant policy and to provide a focus for social media activity by giving people moved by Sarah’s situation something they could do. It stated:

To: Kathleen Sebelius, Secretary, Health and Human Services  
John Roberts, President, Board of Directors, OPTN/UNOS

Please reconsider the policy that excludes children under 12 from receiving adult lungs based on medical necessity. And we implore you to start by making an immediate exception for 10-year-old Sarah Murnaghan, who has been on the lung transplant waiting list for 18 months...Please give her the chance to receive the adult lungs she needs to save her life. (Family and Friends of Sarah Murnaghan, 2013)

The petition drive was spurred largely by Facebook and Twitter. Although Team Sarah had considered creating a dedicated Facebook page for Sarah, it decided to continue using Janet Murnaghan's personal Facebook page because so many journalists and supporters already followed it. Janet Murnaghan accepted every friend request and had about 6,000 Facebook friends, Simon said. In addition to tweeting frequently under the hashtag #sign4sarah, team members Jill Monahan and Tracey Santilli said they scanned Twitter for influencers who might be persuaded to take an interest in Sarah's case and share the petition link with their followers. Santilli said pop singer Katy Perry and one of the stars of the TV show *The Real Housewives of New Jersey* were among the celebrities who retweeted the information.

"At first, it was 'woo hoo,' we got 500 signatures in the first four hours," Garrity said. "By the time Sarah had spent 100 days at CHOP, we reached 100,000 signatures." Team Sarah marked that milestone with an emailed media update, tweet, and Facebook update with photos. The *Los Angeles Times* noted:

Each time someone signed the petition, another email appeared in the inbox of Dr. John Roberts, chief of transplantation at the University of California San Francisco and president of UNOS. 'Children should be at the top of the list,' one email said. 'I don't want Sarah to die,' said another...Roberts' inbox crashed after about 48,000 emails. (Zaremba, 2013, p. A1)

Team Sarah also had to contend with a flood of social media that neither they nor the Murnaghans sponsored. The social media swirling around Sarah's case was not unique; any nationally prominent issue can spark unintended and uncontrollable social media dialogue. On the plus side,

Team Sarah knew that the more social media attention Sarah's case attracted, the greater the level of awareness. But team members were also concerned that competing online petitions, tweets with multiple hashtags, and unofficial Facebook pages such as "Save Sarah," "Donate a Lung to Sarah Murnaghan," and "Sarah will Win" could confuse journalists and the public, especially when inaccurate and even malicious information was disseminated. Team member Nicole McLane said that although most people who discussed Sarah's case on social media were well meaning, Team Sarah was concerned about a possible "renegade storyteller" or "people trying to reframe the story." Simon noted that some of Sarah's supporters even called the media with "updates" about Sarah.

Although Team Sarah felt it was impossible—and unwarranted—to try to control unofficial social media, they knew it was very important to ensure that journalists were not misled by it. According to a national survey of journalists, 65% of reporters and editors use social media sites such as Facebook and 52% use Twitter when researching stories ("National," 2010). Team Sarah managed the situation by staying in almost daily contact with journalists, offering a steady stream of updates and reminding them that Team Sarah and Janet Murnaghan's Facebook page were the only "official" and credible information sources. "The press was very respectful of the Murnaghans," Simon said. "We felt we had to be on call 24 hours a day to protect Sarah. If the media didn't get everything they needed from Team Sarah, they would go to the family" or elsewhere.

### **Political Outreach**

Team Sarah recognized that political officials could help put pressure on DHHS, OPTN, and UNOS and reinforce news coverage and social media attention. Team members reached out to Pennsylvania Governor Tom Corbett and members of the Pennsylvania congressional delegation to urge them to support a policy change to give children and adults equal access to donor lungs. Several political officials sent letters to Kathleen Sebelius, then secretary of DHHS, urging that the transplant rule be overturned; they also issued supportive news releases and did media interviews. On May 31, 2013, Sebelius asked UNOS to review its policies on patients needing lung transplants but did not mention Sarah (Todt, 2013b). A spokesperson for UNOS said that any change likely wouldn't come soon enough to benefit Sarah (Todt, 2013b).

Team member Anne Bongiovanni urged aides to U.S. Representative Lou Barletta, of Pennsylvania's 11th congressional district, to ask Barletta to question Sebelius about Sarah's situation when Sebelius testified at a House budget hearing on June 4, 2013. "It was the first public grilling of Sebelius on the case," Bongiovanni said. But Sebelius refused to intervene on Sarah's behalf, noting that 40 adults in Pennsylvania also needed lung transplants: "The worst of all worlds, in my mind, is to have some individual pick and choose who lives and who dies. You want a process where it's guided by medical science and medical experts" (Hollander, 2013, p. 9).

### **A Sudden Ruling**

After Janet Murnaghan posted a Facebook message on May 28, 2013, seeking pro bono legal counsel, Team Sarah helped the Murnaghans find an attorney, Stephen G. Harvey. On June 5, 2013, he filed suit on behalf of the Murnaghans in U.S. District Court against DHHS and Sebelius. The same day, Judge Michael M. Baylson issued a temporary restraining order instructing Sebelius to immediately suspend DHHS policy in Sarah's case (Good & Boudreau, 2013). This was unexpected but welcome news to the Murnaghans and Team Sarah. "Everyone was shocked that things had changed so quickly," team member Jill Monahan said. Reporters noted the abrupt change as well: "Just yesterday, Health and Human Services Secretary Kathleen Sebelius told a congressional panel she would not interfere in the lung transplant decision of a 10-year-old girl dying of cystic fibrosis. Today, a federal judge ordered her to do just that" (Resnick, 2013, para. 1).

Team member Nicole McLane was driving home from school with her 6-year-old triplets when Team Sarah got a call about the judge's decision. McLane pulled into a parking lot and put a *Tinkerbell* movie in the van's DVD player to occupy her children. Meanwhile, Simon took the call on her cell phone in a home closet—a quiet place away from her children—and Bongiovanni joined from CHOP. In 40 minutes, they wrote a media statement on behalf of the Murnaghans:

...For us, this means that for the next 10 days, Sarah's placement in the queue for adult lungs will be based on the severity of her illness, and she will not be penalized for her age...We are

experiencing many emotions: relief, happiness, gratitude and, for the first time in months, hope. ("Expanded," 2013, para. 2-3)

Team Sarah also notified journalists that a news briefing would take place later that day across the street from the hospital, an outdoor location necessitated by CHOP's ban on news media. It occurred the same day as major breaking news in Philadelphia: a building under demolition collapsed onto an adjacent thrift store, killing six people. But rather than limiting attendance at the news briefing, Simon said attendance actually increased because television networks already had satellite trucks and news crews in Philadelphia to cover the accident.

### **First Transplant**

Developments continued rapidly in Sarah's case. On June 10, 2013, OPTN's executive committee passed a resolution allowing children under 12 to be considered for adult lungs on a case-by-case basis by a panel of transplant surgeons (Goodnough, 2013). That change would expire on July 1, 2014 unless the board of directors made it permanent. On June 12, 2013, CHOP announced that adult donor lungs had become available for Sarah. As journalists waited outside the hospital during the six-hour procedure, Garrity and Simon walked around to tell them that Team Sarah would hold a news briefing afterward (see Figure 3). Team Sarah also released a brief, upbeat media statement on behalf of the Murnaghans, which began: "We are thrilled to share that Sarah is out of surgery. Her doctors are very pleased with both her progress during the procedure and her prognosis for recovery" (Team Sarah, 2013a).

Because CHOP declined to release details of the surgery due to patient privacy (Sheridan, 2013), the first stories about the transplant relied almost exclusively on information from Team Sarah. CNN called Simon "a family spokesperson" and attributed some information to her while also quoting from the media statement: "We expect it will be a long road, but we're not going for easy, we're going for possible" (Carroll & Welch, 2013). Reuters ("Mother," 2013) and Agence France Presse (Sheridan, 2013) also quoted from the statement: "We are elated this day has come, but we also know our good news is another family's tragedy. That family made the decision to give Sarah the gift of life—and they are the true heroes today."



**Figure 3.** Janet Murnaghan talks with journalists outside CHOP after Sarah's first transplant. Source: Associated Press.

But the positive tone grew chillier as journalists sought additional sources for follow up stories and people commented on social media. "Everyone was so happy," Simon said. "Then the backlash started." ABC News noted that Sarah "may have gotten a boost from public attention before her lung transplant...but now that it's over, some of that attention has turned negative," including disapproving comments on news media websites and Facebook (Lupkin, 2013). Peter Johnson Jr. of Fox News called disparaging Facebook posts about Sarah and her family "hate speech," adding, "It makes me ashamed to be an American" ("Makes," 2014, para. 3). Several critical editorials and commentaries also appeared. The *Chicago Tribune* editorialized: "Sarah's parents are elated. We rejoice with them. But we think that this case should not set a legal precedent...Transplant decisions should be driven by medical professionals, not by the courts" ("Editorial," 2013, para. 7-10). And Scott Halpern, a physician and ethicist at the University of Pennsylvania, asserted that legal and political officials "bent the rules in favor of a well resourced family that generated enormous media attention" (2013, p. 385). But other views in the media were sympathetic:

If I were the parent of a child who might be kept alive by a lung transplant, I too would move Heaven and Earth to get it done. That the parents of 10-year-old Sarah Murnaghan have made her an Internet and cable news celebrity in a desperate effort to get her on the adult list for a lung transplant is completely understandable. No one with a particle of human sympathy can fail to be moved by the family's situation. (Charen, 2013)

## **Second Transplant**

After the news briefing, Team Sarah heard very little from the Murnaghans. At first, team members thought the family was just focusing on Sarah's recovery. But Monahan said continued silence was the first indication something had gone wrong. Garrity said she kept checking Janet Murnaghan's Facebook page and "got a really bad feeling" when nothing new appeared. Santilli said reporters called Team Sarah to ask why there were no updates on Sarah's condition, since there had been frequent updates before the transplant. Simon said she got a tip from a reporter that Sarah was going to have a second transplant because the first lungs had failed, but the Murnaghans did not tell Team Sarah until 12 days after the second operation took place on June 15, 2013. CHOP had not announced the second transplant either. "It made our team very uncomfortable to have been left in the dark," Simon said, especially since many CHOP employees had known.

Part of Team Sarah's discomfort over the Murnaghans' silence was personal: team members had volunteered for a month on the campaign, cared deeply about Sarah, and felt puzzled and even a bit let down by Sarah's parents. But part of team members' discomfort was professional: their reputations as public relations professionals were on the line. Team members had worked to build positive relationships with journalists covering Sarah's story, updated them almost daily, and strived to persuade them that Team Sarah and the Murnaghans were the only "official" and credible information sources. How would journalists feel now? Would they think that Team Sarah shared information only when it met the needs of the family—and not the needs of the news media? And would they continue to rely on Team Sarah and the Murnaghans? As Monahan noted, "The family had been so conscientious about keeping the media informed every step of the way and now it was just the opposite."



The Murnaghans' delay in informing Team Sarah about the second transplant gave the team little time to prepare for the media. The story was also more complex this time: Why had the first transplant failed? Why was Sarah put through two grueling surgeries in three days if doctors knew in advance that the first lungs were in poor condition? Why were the odds better for the second transplant even though those lungs were infected with pneumonia? And while it may have been fair to give Sarah one set of lungs, why did she deserve two? Team members said they were also hampered by the lack of a medical expert who could explain terms and procedures and to whom they could also refer journalists. Sarah's doctors, who would have been the best spokespeople, could not comment because of CHOP's policies. "It would have been incredibly helpful to have had access to a physician to help translate what was happening," Garrity said.

Team Sarah issued a media statement on behalf of the Murnaghans on June 28, 2013, shortly after learning about the second transplant. In contrast to the breezy, half-page statement Team Sarah wrote after the first transplant, this sober, two-page statement provided considerable detail on why the first transplant had failed, how Sarah was placed on a heart and lung bypass machine afterward, and why she had a second transplant just three days later. Notably, the statement also attempted to explain why the Murnaghans had delayed announcing the second transplant for almost two weeks:

After we announced the overwhelmingly joyful news on June 12 that Sarah's (first) lung transplant was a success, things quickly spiraled out of control. Though we had made Sarah's battle very public, we were completely emotionally unprepared for what was to come...That evening, as we waited for Sarah to be transitioned back to her room, an emergency code blue was announced. Sarah's vital signs had begun descending rapidly as her new lungs started to fail. (Team Sarah, 2013b)

The statement noted that on June 21, 2013, seven days after the second transplant, Sarah underwent another surgery to close her chest, which her doctors had kept open for healing. Afterward, Sarah was slowly brought out of her induced coma:

It was only then that we could allow ourselves to feel real hope...Her health was so precarious and we were so physically, mentally, and emotionally drained that we kept some of what was going on at the hospital private. Her care and being by her side has been our focus. (Team Sarah, 2013b)

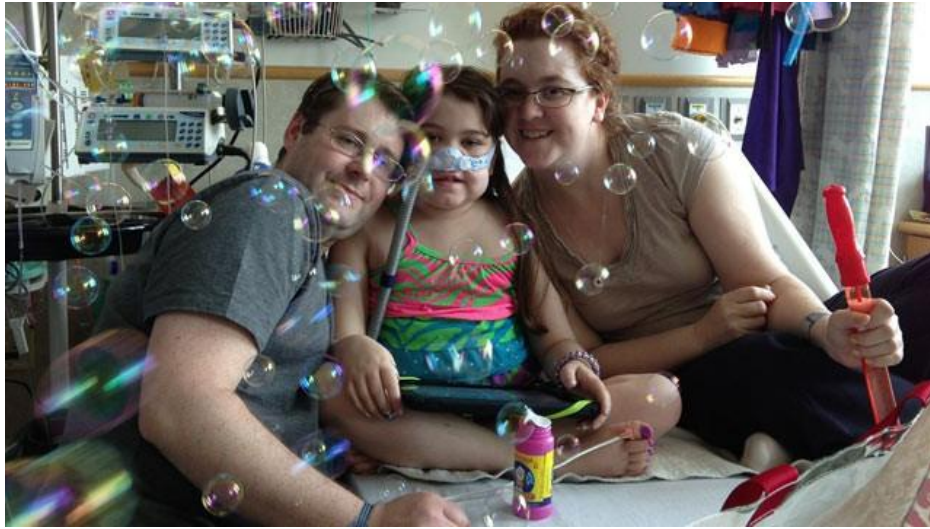
Stories on the second transplant did not criticize the Murnaghans for the lack of communication; rather, the tone was compassionate: “Sarah’s family says they waited until now to tell her story because it was too hard to talk publicly when they thought they might lose their child,” NBC News reported (Snow, 2013).

### **Going Home**

For the next two months, Sarah made slow but steady progress, including getting off supplemental oxygen and using a walker to go short distances (Avril, 2013). Team member Rachael Schwartz said Team Sarah updated the media on every milestone, including the celebration of Sarah’s 11th birthday at CHOP on August 7, 2013. Heartwarming photos taken by the family and shared by Team Sarah—including one of Sarah on her hospital bed with her parents, the air full of colorful bubbles—kept circulating in the news media and on social media (see Figure 4). “Any time we had new video of Sarah to share with the media, it was golden,” Simon said.

CHOP announced that Sarah would be ready to go home on August 27, 2013. Garrity said Sarah’s parents had wanted journalists to see their daughter walk out of the hospital, and Team Sarah also favored a media availability outside CHOP, but Sarah wasn’t physically up to it. Team Sarah was concerned about negative perceptions from photos and video of Sarah being put in an ambulance at CHOP or taken out of an ambulance at home. The Murnaghan home was the obvious next choice for a news briefing, but Team Sarah worried about the family’s privacy. Ultimately, the team decided to hold the event outside the home shortly after Sarah’s return.

Sarah’s homecoming was the lead story on the front page of the *Philadelphia Inquirer*. It was accompanied by a photo of Sarah sitting in an armchair outside the front door, which was festooned with a welcome home sign, balloons, and wreath of pink flowers (see Figure 5). Sarah was flanked by her parents, and her three siblings were nearby. The moving story began:



**Figure 4.** Sarah between her parents, Fran (left) and Janet Murnaghan, as they blow bubbles in Sarah's hospital room. Source: Murnaghan family photo.



**Figure 5.** Sarah and her parents and siblings at a news briefing outside the family's home after her homecoming on August 27, 2013. Source: *Philadelphia Inquirer* photo/Clem Murray.

It has become a cliché to call critically ill children “fighters.” But there is no better word to describe Sarah Murnaghan, the girl who, with equally indomitable parents, has battled cystic fibrosis, national lung allocation rules, and the rigors of double lung transplant surgery—twice. (McCullough, 2013b, p. A1)

ABC News also called Sarah a “fighter” who had “so many rooting for her” (“11-year-old,” 2013). Other stories were equally touching:

The first thing Sarah Murnaghan did when she got home Tuesday morning was ask her sister to fetch their dolls so they could play. For most 11-year-old girls, that might be an everyday event. But for Sarah, who spent months in the hospital and received new lungs only after her family filed a lawsuit, it was extraordinary. (Mai-Duc, 2013)

Sarah’s parents came across in the stories as devoted and determined. “Always advocate for your children. Always,” Fran Murnaghan was quoted as saying (Dale, 2013, para. 20).

### **Moving Forward**

Team Sarah continued to look for milestones to keep in touch with the media because OPTN planned to make a permanent decision on the transplant rule by July 1, 2014. “We wanted to keep the story alive,” Simon said. “It would have been irresponsible of us not to continue.” However, Team Sarah became much more selective about pursuing media opportunities to allow Sarah and her family time to continue healing. Sarah has been out in public, and in the news, only a few times since returning home. But her case was included in several end-of-the-year national media stories and on lists of top health stories of 2013. And some journalists who developed close relationships with Team Sarah and the Murnaghans have followed up regularly on Sarah’s recovery. Stories have spotlighted how far Sarah has come since her transplants, such as hanging ornaments on her family’s Christmas tree (Aleccia, 2013b) and riding a pink bike down the street with her siblings (Lupkin, 2014).

The post-homecoming stories perpetuated the upbeat tone of previous media coverage by highlighting Sarah’s spirit. For example, NBC’s *Today Show* interviewed Sarah and Janet Murnaghan at their home in February

2014 after Sarah received an award from the local chapter of the Cystic Fibrosis Foundation. The uplifting story began: “What a remarkable little girl. Now, some eight months after two transplants, Sarah is doing great” (Dahlgren, 2014). The story included family video of Sarah being applauded at the ceremony, followed by Sarah reading from her speech: “Whatever you are dealing with—young or old—just be yourself. Look deep inside yourself for that bravery and the reason to fight.” The story ended with the reporter remarking: “Isn’t she amazing?” (Dahlgren, 2014).

### **Evaluation**

Team Sarah estimates that Sarah’s case generated six billion trackable impressions as the story reverberated in the news media, on social media, and in the political arena for months. Thousands of stories appeared in media outlets throughout the U.S. and in foreign countries, including Britain, South Africa, Turkey, Jordan, Bangladesh, New Zealand, and Australia. But just as important as the amount of coverage was its overall sympathetic and positive tone. The vast majority of stories expressed empathy toward Sarah and goodwill toward her family.

Sarah’s story also resonated on social media, where Team Sarah’s online petition to allow transplants of adult donor lungs to children became one of Change.org’s most popular petitions of all time, with 373,118 supporters (Family and Friends of Sarah Murnaghan, 2013). In addition, Team Sarah garnered support from Pennsylvania Governor Tom Corbett and four members of congress from Pennsylvania. Their news releases, media statements, and appearances on C-SPAN also helped put pressure on DHHS, OPTN, and UNOS. Team Sarah also helped the Murnaghans find a pro bono attorney for Sarah’s case, and his successful legal efforts put the lung transplant rule on hold.

But the best measure of success is that Team Sarah’s campaign helped suspend U.S. lung transplant policy in only three weeks, paving the way for Sarah to get the lungs for which she had been waiting 18 months. That achievement helped Team Sarah win the PRWeek award for Public Affairs Campaign of the Year in March 2014 (see Figure 6). One of the judges said that Team Sarah’s efforts “simply blew us away. For no budget, its achievements—saving Sarah and paving the way for others to benefit—



**Figure 6.** Team Sarah receives the 2014 PRWeek award for Public Affairs Campaign of the Year. From left: Tracey Santilli, Anne Bongiovanni, Rachael Schwartz, Nicole McLane, Tracy Simon, Maureen Garrity and Jill Monahan. Source: Tracy Simon.

are nothing short of miraculous” (“Team Sarah,” 2014, para. 1). Eleven other children under 12 years old were also granted exceptions to the lung transplant rule after Sarah received new lungs in June 2013, although three died while awaiting transplants (Aleccia, 2104).

In June 2014, the board of directors of OPTN voted to make the transplant rule change permanent (Aleccia, 2014). Janet Murnaghan said she was thrilled by the vote, saying it was a hard-won victory not only for Sarah, but also for other children like her: “More children will be fortunate enough to receive life-saving lung transplants,” she said (Aleccia, 2014). Sweet, OPTN’s board secretary, said Sarah’s case had prompted him to re-think his position on lung transplant policy: “On day one of this story, I said it’s a zero-sum game and we have a policy and we shouldn’t change it,” he said (Aleccia, 2014). But Sweet said he now believes children deserve the benefit of the doubt when being considered for lung transplants, and he doesn’t fault the Murnaghans for advocating so

vigorously for Sarah. “I think the system wouldn’t have changed as fast if the Murnaghans hadn’t gotten involved,” he said (Aleccia, 2014).

### **Analysis & Discussion**

As one of more than 121,000 Americans needing transplants, Sarah’s situation was not unique. Nor, unfortunately, was it atypical that Sarah had been waiting for 18 months for new lungs while her condition deteriorated. But the resources her family was able to marshal on her behalf were unusual indeed. Her mother was a former public relations practitioner who appealed to former co-workers and other local strategic communicators to bring Sarah’s story into the national spotlight. Members of Team Sarah were experienced professionals with strong media contacts and social media savvy who were moved by Sarah’s plight to volunteer. Team Sarah also helped the Murnaghans find a pro bono attorney to take Sarah’s fight to court—and win. These resources were more significant factors in Sarah’s case than economic class, race, or prominence. While there have been periodic controversies over whether some patients, including Apple Inc. CEO Steve Jobs, used their wealth, celebrity, or influence to bend the rules and receive a transplant sooner (Perrusquia, 2013), neither the extensive strategic communication support nor the successful legal counsel cost the middle-class Murnaghan family a dime.

Although Team Sarah’s campaign was unprecedented in magnitude and impact (Halpern, 2013), other patients and their loved ones have long used some of the same tactics to raise money and plead for organs. A UNOS spokesperson said it was not uncommon for patients to use Facebook and Craigslist to find donors: “We see more and more people matched up by social media...Before the Internet, people found other ways: through a church bulletin, word of mouth, or an advertisement” (Blankinship, 2012, para. 6). For example, a woman in New York who has been waiting two years for a kidney transplant said she “regularly updates her Facebook page, tweets, posts ads on Craigslist, hands out fliers at church and hangs signs on grocery store bulletin boards” (Lerner, 2014). Some patients awaiting transplants also appeal to the news media. Journalists can play a “pivotal role” in deciding which patients get attention, which “may mean the difference between life and death” (Baldwin, 1994, p.41). Being a cute child or coming up with a creative stunt are the surest ways to get publicity (Baldwin, 1994). For instance, an

elderly South Carolina man walked 250 miles while wearing a sandwich board reading, “Need Kidney 4 Wife,” which drew national news coverage (Hartman, 2012). But some patients and their families have limited time to spend on social media and publicity; others lack skills or know how. Very few have access to public relations counsel because they cannot afford to hire practitioners or lack connections to find pro bono assistance.

Team Sarah capitalized on all the ingredients in Sarah’s case to transform what might have been a one-day news story into a long-lasting media phenomenon. These ingredients included a brave young girl near death, devoted and resolute parents, alleged discrimination against children, government officials criticized as heartless, and basic notions of fairness. Team Sarah also benefitted from its members’ expertise, which minimized ramp-up time; the Murnaghans’ personal trust, which enabled the team to communicate without delays for approval, thereby never missing a news cycle; and ardent family spokespersons, especially Janet Murnaghan, who “instantly thought like a television news producer,” Simon said. Other resources included digital technologies such as Facebook and Dropbox, which enabled members to share information nimbly with each other and the media; and members’ availability around the clock, which helped ensure that journalists’ needs were met and the family’s privacy protected.

Due to the information vacuum from CHOP and Sarah’s doctors, media coverage of Sarah’s case relied heavily on information and access carefully controlled by Team Sarah on behalf of the Murnaghans. Scholars note that “the greater the information scarcity, the better the chance that sources that control that information can influence the media agenda” (Zoch & Molleda, 2006, p. 294). Stories replicated the key messages in Team Sarah’s communication materials, quoted remarks by Sarah’s parents and aunt at news briefings Team Sarah organized, and were often accompanied by compelling family photos and video Team Sarah distributed.

While journalists found other sources for some stories, including physicians not involved in Sarah’s case, bioethicists, political officials, and spokespersons for UNOS, they depended most on Team Sarah. This often shaped to a large extent what was included in stories, including messages about fairness, discrimination against children, perseverance, and hope.



That was exactly how Team Sarah and the Murnaghans preferred coverage to be delimited to create the most support for Sarah and the greatest impetus to change transplant policy.

For example, there was scant examination by journalists of whether Sarah's post-transplant prognosis was as optimistic as her parents described, which had affirmed perceptions of Sarah's "worthiness" for two sets of donor lungs. In stories about the news briefing outside the family home after Sarah's homecoming, Janet Murnaghan was widely quoted as saying:

She'd like to be on a soccer team. She used to horseback ride and ice skate, and she's looking forward to doing those things again. We're looking forward to Sarah having a nice, long life, going to college, getting married, having a family and doing everything that we dream for our other kids. (Leach, 2013)

Although those rosy predictions went unchallenged in many stories, *USA Today* interviewed Ashish Shah, lung transplant director at The Johns Hopkins Hospital in Baltimore (Hellmich, 2013). He said that about a third of lung transplant recipients live for 10 years after surgery, adding: "It's definitely possible that she'll be running around playing soccer, but it may be a year from now" (Hellmich, 2013, p. 3A). But when expert sources were used to provide a "reality check" on Sarah's prognosis, their views were at or near the end of stories while the comments of Sarah's parents were more prominent.

The media's reliance on Team Sarah also increased the likelihood that certain elements were minimized in or omitted from stories. Some journalists became so caught up in the human-interest aspects of Sarah's case that the ethical issues were marginalized. For example, stories seldom explained that if Sarah got donor lungs, another patient would not, and that if children under 12 were eligible for adult lungs, some adults would no longer get them. Stories also rarely discussed the donor organ shortage and ways to increase the supply. An exception was the *Times-Tribune* of Scranton, Pennsylvania, which editorialized that "regardless of how the gut wrenching saga of 10-year-old Sarah Murnaghan plays out, her case is a reminder of the pressing need for organ donations" ("Many," 2013, para. 1). And NBC News noted that only 45% of adults are organ

donors, “a figure that...seems tragically low when the public’s attention is riveted on the lack of organs for a child such as Sarah” (Aleccia, 2013a).

The significant impact of Team Sarah’s campaign made it an example of effective strategic communication. But its impact also raised questions and concerns among some ethicists and physicians. Since transplant policy aims to be equitable for all patients, “not just for one heart wrenching case” (Neergaard, 2013, para. 3), is it fair, as bioethicist Caplan asked, to “use PR or otherwise campaign to get to the head of the line?” (Sheridan, 2013, para. 19). Halpern, of the University of Pennsylvania, noted that “people might rightly ask whether it’s fair for lungs to be allocated to people who can create the biggest media splash” (“11-year-old,” 2013). And Daniel Wikler, a medical ethicist at Harvard University, said that if transplants are based on “the success of individual publicity campaigns, with organs going to those who hire the best PR firms and lawyers, who on the waiting list would remain confident that their priority would be decided on the merits?” (Norman, 2013, para. 5).

### **Discussion Questions**

1. Team Sarah reacted immediately to Janet Murnaghan’s Facebook request to generate awareness for Sarah’s plight by sending a media pitch that same day. In your opinion, would it have been better for the team to have first spent time researching the situation and developing strategies, tactics, and key messages before reaching out to the media? If so, why?
2. To what extent did CHOP’s policies, including its ban on news media onsite and not allowing physicians to be interviewed, contribute to journalists’ dependence on information from Team Sarah? When Sarah’s case began to attract so much media attention, do you think the hospital’s public relations practitioners should have tried to figure out a way for CHOP to be included in the story without infringing on patient privacy?
3. The U.S. government rations scarce donor organs through a system designed to be fair to all patients on the waiting list even though the system can seem unfair to individual patients. If you were a public

relations practitioner at UNOS, how would you propose to communicate this seemingly contradictory message?

4. Team Sarah worked to build relationships with journalists covering Sarah's story and felt sidelined when the Murnaghans didn't tell the team about Sarah's second transplant until two weeks afterward. If public relations is about creating and nurturing relationships, what responsibilities do you think public relations professionals have to journalists to keep them informed? What competing pressures may public relations professionals face?
5. Even before Team Sarah, people needing transplants have turned to social media and the news media to plead for organs. Because of the steadily increasing gap between donor organ supply and demand, do you think the stakes are higher now in terms of what patients and their loved ones are expected to do to get a transplant? Where may this lead?
6. High-profile medical cases like Sarah's result in less attention paid to all other cases. But what if every patient who needed a transplant, experimental drug, or prohibitively costly operation had their own Team Sarah? Would the news media and social media become sated with these human interest stories? Would the impact of strategic communication efforts diminish?

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