HEALTH

I Was All Set to Become the Most Popular Guy in the Cancer Ward. Then I Met My Nemesis: Ben.

WRITTEN BY LUKE MULLINS | PUBLISHED ON **DECEMBER 11, 2016**

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It was late afternoon in the cancer center, and I was wiped out from my daily zap of chemotherapy. The final drips were washing through my IV, and as usual, I was slumped in my green recliner, blank-faced and stone quiet.

I was about four months into treatment, and the chemotherapy had overwhelmed my system. My kidneys had all but shut down. I'd been repeatedly hospitalized for treatment-related panics. My spirit had completely surrendered.

This certainly wasn't the case for Ben. The same chemicals that had turned me into the hospital's resident grump had made him an oncology-floor legend, the most popular guy in the cancer center, the only patient whose vitality seemed to increase with each round of chemo.

As I moped in the corner, a group of nurses huddled around Ben's chair, their laughter reverberating throughout the room. Next, Ben pulled an older gentleman aside to offer encouragement. "You're wife's going to be feeling a whole lot better," Ben told the man, "once she gets that blood transfusion."

Finally, Ben popped out of his chair.

"Well, that's it," he announced to the room. "Another day down."

Dear God, how I hated Ben.

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In the winter of 2015, I noticed a lump on my left hip. It had appeared out of nowhere: squishy along its periphery but firm in the center, painless, and about the size of a peanut. I became fixated on it. Each night in bed, I poked and squeezed the rubbery mass to try to determine if it was growing.

After months of obsessive self-examinations, I went to a dermatologist for a biopsy. It took five weeks for the results to arrive. As each day passed, I became more convinced that the lump was malignant. Did I have six weeks to live? Did I need an organ transplant? I forced myself to get out of bed but spent all day analyzing various scenarios of my death.

Finally, the doctor called. I had Ewing sarcoma, a rare type of cancer that forms in the bone or soft tissue—in my case, the hip—and often migrates to the lungs, where it can become fatal. The good news: We'd caught the cancer before it spread. Within 48 hours, a surgeon had removed the tumor, and follow-up tests showed no traces of the disease anywhere in my body.

After the surgery, I joined my girlfriend, Christina, and my brothers at my parents' house to celebrate the good fortune. I was floating on adrenaline, as if I had just walked away from a plane crash.

> The author, Luke Mullins, at the Sibley Hospital cancer center. All photographs courtesy of Luke Mullins.

But my diagnosis came with bad news, too: Ewing sarcoma has a nasty history of returning even after its tumors have been excised. I was looking at a year of chemo.

As any high-school football coach can tell you, the only thing you can control during times of adversity is your attitude. And I'd watched enough medical procedurals on TV to know that the plucky cancer patient with the positive outlook is always the real hero. So from the moment I was diagnosed, I understood that my attitude during chemotherapy would be viewed as the defining expression of my character.

I approached chemo with the same sense of detachment I'd use to research an article. I didn't consider myself a real cancer patient; I was still relatively young—37 at the time—I was in decent enough shape, and my prognosis was favorable. (After completing treatment, people with early-stage Ewing sarcoma, like me, typically have five-year survival rates of around 70 percent.) Instead, chemotherapy would give me an inside look at what *it's like* to have cancer.

Given my optimistic prognosis, I was certain I could assume the posture of an easygoing, almost curiously upbeat patient—the polar opposite of the cowering spaz who'd melted down while waiting for his biopsy results. I envisioned myself cruising through treatment like the hilarious and lovable patient on a hospital sitcom. Nurses would fill me in on the oncology-floor gossip, doctors would swing by for a well-deserved laugh, and fellow patients would gather strength from my flashes of wisdom.

"Sometimes I forget Mr. Mullins is even a patient," one nurse would say to another. "I wish everybody had his attitude."

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Each chemo regimen is as unique as the disease it's intended to fight. Ewing sarcoma is rare, and researchers haven't been able to develop for it the kind of targeted chemotherapies that exist for more common cancers. As a result, my doctor warned me, my treatment would be harsh.

I paid no attention. I was still elated that my diagnosis wasn't certain death, and I didn't want any bad news ruining my casual outlook. As the first day of chemotherapy neared, I joked about contacting the Make-a-Wish Foundation—maybe it could arrange a private meeting for me with Justin Timberlake? When I filled out the admissions paperwork at the hospital, the administrator asked who I'd want to make medical decisions on my behalf in the event of incapacitation. Christina and I discussed, at some length, assigning this responsibility to Wilson Ramos, the catcher for the Nats. (We eventually settled on my father.)

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When the nurse entered the hospital room to connect me to the IV, she couldn’t tell whether Christina or I was the patient. We all had a nice laugh about this—I was delighted that the nurse thought I looked so healthy. Later that night, my brothers, Brody and John, arrived with a cooler of beers. I put the Nationals game on; they cracked open the cans and offered me one. It was really quite tempting—I felt no effects of the drugs, and I wanted to share in the warm family moment. Still, I decided to pass.

Two days later, I slunk out of the hospital in a haze of disbelief. The drip of vicious fluid had—painstakingly, over 48 hours—decimated the arrogance I’d arrived with. I was exhausted, pale, bloated, and nauseated. My legs wobbled. My skull throbbed. My urine was bright orange.

My emotions were just as scrambled. I was stunned by how violently the chemotherapy had landed on me, and humiliated by how willingly my body had capitulated. Above all, I was ashamed. I had approached cancer with apathy and conceit, and in so doing, I had trivialized the suffering the disease has caused for so many others. I no longer felt like a detached journalist studying a deadly illness. Now I was a cancer patient.

As Christina and I hobbled to the car, I felt as if I’d just lost the big game.

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I was out cold the entire next week. The chemicals had jumbled my senses. Water tasted like aluminum foil, and my nose became supersonic. I could smell odors in soaps and shampoos that I’d never detected before. Sores formed in my mouth, making food painful to eat. My hair fell out, eyebrows and armpit hair included. My stomach curdled, and my insides were gridlocked by constipation. My arms and legs became cinder blocks. Descending the stairs was out of the question. I remained in bed all day and night.

One morning the following week, I woke with a fever. Christina drove me to the hospital, and I stayed for two nights getting intravenous antibiotics. I was still groggy when I began my second round of chemotherapy a couple of days later. By day three of the weeklong treatment, my mind was swimmy. I couldn't remember which day it was.

> **"I WAS STUNNED BY HOW VIOLENTLY THE CHEMO HAD LANDED ON ME, AND HUMILIATED BY HOW WILLINGLY MY BODY HAD CAPITULATED. ABOVE ALL, I WAS ASHAMED."**

The next morning, I excused myself to the bathroom, where—for the first time in days—I successfully moved my bowels. It was a nice development, and for several minutes I remained still, enjoying my small victory over constipation. That's when everything started to change. Rich green grass poked out of the tile floor beneath my feet, and two banks of stadium lights illuminated the night sky. An entire football team and a marching band walked, one by one, into the room. The players wore orange-and-black uniforms; the tuba player was fat.

Tests soon showed that my kidneys had shut down. This trapped the chemotherapy inside my system, and it accumulated enough strength to produce hallucinations. The doctors said I'd need fluids and rest.

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It was during this time that my attitude fell apart.

Before visiting the doctors or nurses, patients gathered in a waiting room where a woman I'll call Nurse Johnson read our names off a clipboard and led us inside. Nurse Johnson was instinctively cheerful, and each morning she greeted us with a comedic routine perfectly calibrated for the room's mostly older crowd.

“Oh, no! Not you again, Mr. Fitzgerald!”

“Ms. Schultz? Shouldn’t a young lady like yourself be on the pediatric ward?”

It’s impossible to overstate just how well these jokes landed. The spasms of laughter were hysterical enough to dislocate ball-and-socket joints. But the chemo and the kidney problems had left me sick, exasperated, and angry. I found Nurse Johnson’s act annoying, and it bothered me to see everyone else having fun.

The infusion center, where patients received chemotherapy, was even worse. The room was lined with cubicles containing large reclining chairs and televisions. Clear plastic tubes stretched from the patients to bags of fluid above their heads. I had expected this to be a sad, hollow place. But to my astonishment, everybody seemed to be having a good time. Mothers played lighthearted card games with their adult children. An attractive young couple snuggled beneath a blanket while watching a movie on a laptop—get a room!—and nurses listened patiently to older gentlemen tell stories about their grandchildren. Everyone was acting as if this were summer camp, while I felt like death.

The disconnect felt particularly stark on October 30, 2015, the day before my 38th birthday. Treatment that day called for several drugs, and before each could be dripped into my IV, the nurses had to follow a specific protocol to ensure they gave me the correct medicine.

“Okay, name?” the first nurse asked.

“Luke Mullins.”

“Date of birth?”

“October 31, 1977.”

“You were born on Halloween?”

I’d always taken pride in my Halloween birthday. People got a kick out of it, and it was easy to remember. But I was hoping this year’s would just fly right by.

“Yeah,” I said in an exaggerated groan, intended to signal that there was no need—on this fifth and final day of a grueling week of chemotherapy—for any acknowledgment.

“Oh, my gosh!” she said, eyes bursting with excitement. “What are you doing to celebrate?!”

“Nothing,” I snapped.

An hour later, a new nurse came by to confirm my identity for the next drug. She was even more impressed: “Halloween is your birthday?!”

We repeated this exercise throughout the rest of the day as different nurses rotated through. Each appeared troubled by my aversion to fun. As I lay in the cancer center—cold, exhausted, barely functional—I got the distinct sense that I was being judged for wasting a birthday that so many others would have killed for.

Later that afternoon, Nurse Johnson popped in wearing a goblin mask. The room exploded in laughter. I closed my eyes and pretended to be asleep.

Right about this time, I identified the ringleader of this godforsaken positivity: the patient named Ben. He was about my age but more stylishly dressed and better-looking. While I sulked in my chair, he streaked through the infusion center like an SEC punt returner. Everybody loved him. When Ben entered the room, the entire staff turned out to greet him, as if he were Norm from *Cheers*.

Ben was classy and inspiring, and I immediately decided I could not stand him. Truth is, I was jealous: He had achieved—without effort or intent—the attitude I had envisioned for myself when I learned I would need chemotherapy. He must have a glowing diagnosis and a cakewalk chemo schedule, I thought.

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One morning in the fall, a high-school friend visited me during treatment. We chatted for a couple of hours, and at some point he said something that made me laugh.

Overhearing this, Nurse Johnson said: “You got Mr. Mullins to laugh? I didn’t think anyone could get Mr. Mullins to laugh!”

While Ben had emerged as the cancer center’s celebrity, I’d begun to feel like the outcast. The reputation bothered me, but I was far too sick to change it. Instead, I took comfort in the two people on the medical staff with whom I was closest.

Dr. Katherine Thornton, my oncologist, is one of the country’s leading sarcoma specialists—patients traveled from several states away to see her. While other cancer doctors can be stiff and frigid, Dr. Thornton radiated the warmth of a kindergarten teacher. One morning during treatment, she stopped by my room before any visitors had arrived, and I asked her why she had become a doctor. She said she’d been an artist in New York City—a photographer—in the late 1980s, when her gay friends began dying of AIDS. She enrolled in medical school intending to combat that epidemic but eventually turned her attention to sarcomas. The tumors were mysterious, under-researched, and deadly. People needed her.

Late-stage sarcomas are often unstoppable, and watching patients die is devastating. What kept her going, she said, was the ones who had a chance to recover. “People like you,” she told me.

My primary-care nurse, Mary Cox, poured the chemo into my IVs, poked the needles into my arm for blood tests, and rolled me to the hospital when things fell apart. She was friendly and funny. Although she’d once been a cancer-care administrator, she’d returned to nursing in order to work more closely with patients.

Mullins with Mary Cox.

Dr. Thornton and Mary understood that my body was to blame for my poor state of mind. I looked up to them a great deal, and the three of us became pals. From time to time, however, one of them would mention their other Ewing-sarcoma patient. He was about my age and undergoing the exact same treatment I was. But unlike me, he had breezed right through it. He was doing so well, in fact, that he went on a trip through Europe between treatments. And he was just hilarious—everyone was still chuckling about the giant flat-screen TV and wi-fi hub he'd brought into the hospital so he could watch Netflix during chemo.

Dr. Thornton and Mary were careful not to breach confidentiality, so they never told me his name. But I eventually figured it out: Their other Ewing-sarcoma patient was Ben.

What was this guy trying to do to me? He had sashayed through the same regimen that had reduced me to rubble. He had stolen my attitude when I was too sick to notice. Now—the final insult—he had become more popular with my only two friends in the building. I mean, as if chemo weren't demoralizing enough.

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As complications from treatment persisted, I became convinced I was the only patient in the cancer unit who was actually suffering. Nobody, I thought, had any idea what this was like. I quietly cursed everyone on the elevator who didn't get off on the cancer floor, and I fumed at other patients who chatted casually during their treatments. I sat silent and expressionless for hours.

Things with Christina began to teeter as well. She had put her life on hold to care for me, but I was miserable to be around. When I wasn't at the hospital, I spent most days at home in bed, watching TV and drifting in and out of sleep. I was irritable and short-fused. Disagreements over the remote control devolved into hurt feelings and tears.

During one argument a few months in, Christina told me I had a "bad attitude." Although she never mentioned him by name, she wanted me to be more like Ben. It was an understandable request. This had been an awful year for Christina, too, and she deserved to have a partner through it. But I didn't have the strength, and it offended me that she couldn't understand that. She was still upset when she left my house that evening.

> "WHILE BEN HAD EMERGED AS THE CANCER CENTER'S CELEBRITY, I'D BEGUN TO FEEL LIKE THE OUTCAST."

The next morning, I woke up with a terrible thirst. It was only about 12 feet to the bathroom faucet, but when I sat up in bed, my heart raced as if I were running the 100-meter dash. I felt dizzy and weak. Because Christina and I were fighting, I called my brother John to take me to the hospital. Dr. Thornton helped me onto an examination table in her office as I struggled to catch my breath. Nurses scurried around me. Machines beeped.

I felt helpless. My body was failing—the chemotherapy was too powerful. How could I fight the cancer if I couldn't handle the medicine?

Later that afternoon, Mary wheeled me over to the hospital's cancer wing. Nurses attached heart monitors to my chest and infused me with blood almost continuously over the next three days.

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Two weeks later, I met Dr. Thornton in her office for our regular appointment. "I'm going to change up your treatment," she told me.

The crises I had been through, she believed, were linked to my body's poor reaction to the chemotherapy drug ifosfamide. Her solution was simply to swap out this drug for another. I was skeptical. After all, my rosy prognosis was predicated on successfully completing a specific treatment regimen that included ifosfamide. But Dr. Thornton was confident the change wouldn't reduce the treatment's efficacy. Right about this same time, I had my final infusion of the most potent drug on my treatment schedule, doxorubicin.

These two developments had a profound impact on my well-being. Kidney function improved, shortness of breath dissipated. My hair began to grow back. The days immediately following treatment were still painful, but I didn't need as much time to recover. It was easier to leave the house. I could spend more time at the office or visiting friends. I took long drives, listening to the radio. Christina and I went out to dinner. By the time 2016 got under way, everything was more tolerable.

As the fog of misery lifted, my perception of the things around me improved dramatically. Life went from black and white to color, and the inside of the cancer center looked entirely different. It quickly became clear I wasn't the only one struggling. I could now see the terrified couples in the waiting room. The older, emaciated patients passed out in their chairs. The anxious families huddled around doctors, hoping for good news. There was one man I saw every time. He held his wife's hand and read the Bible as the chemicals dripped into her IV.

Occasionally, a shivering and confused patient was rushed in on a wheelchair. Medical staff would dash over to help as panicked family members circled nearby. It was like watching myself from a few weeks earlier, and it scared me.

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Some of the conversations I overheard were indeed casual, but others were deadly serious. One afternoon, a nurse made a call from right next to my chair. “I’m calling from Sibley Hospital,” she said. “I just sent over some scans from a patient with a brain tumor.”

There was a pause.

“Okay,” the nurse responded. “I’ll let the oncologist know the bad news.”

Another time, I watched two gray-haired female patients greet each other like old friends. “I just got a really good scan,” one exclaimed. “It was the first time it was clean in two years!”

One evening while Christina and I were having dinner at a pizza place near my house, I recognized a fellow patient at a nearby table. He was on a date with a blond woman; both appeared to be in their mid-thirties. It was startling to see someone from the hospital out in the real world, and if I hadn’t recognized him, I never would have known he was sick. It made me think about all the other folks out there suffering, anonymously, from cancer. People soldiering through treatment, worrying about tomorrow, struggling to keep doing the things that make life normal. Like going on dates.

As the life returned to my body, I began to feel tremendously grateful for the many people who had helped me through treatment. Christina, my brothers, and my parents made sure I was never alone in the cancer center. My neighbor mowed my lawn, and colleagues and friends brought meals by the house.

At the same time, I became friendly with the hospital staff I’d once dismissed. During one particular session, a doctor brought in a copy of an article I’d recently written for *Washingtonian* and left it on the nurses’ station for the staff to read. Nurses pulled me aside to ask about it. In the following days, I began to notice other *Washingtonian* issues in the waiting room for patients to read.

The staff understood the hardships of cancer much better than I gave them credit for. One morning while a different nurse drew my blood, Mary stopped by and made a joke about my having lost weight.

"I always tell people," the nurse said, "losing weight is the best thing about doing chemo."

I looked up, surprised. "You did chemo?"

"I did. I was 17. I've been in remission for three years."

The laughter in the infusion center, which had once so enraged me, became my favorite part of being there. Mary and I would keel over recalling details of the chemo-related panics I'd experienced in the fall. Over time, I felt so cared for, so safe, so loved that—even though the chemotherapy itself was sickening—I actually looked forward to my trips to the center.

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I was thrilled with my improved attitude. But there was still, I felt, one thing left to take care of.

It began to dawn on me that all of my friends at the hospital were employees: doctors, nurses, administration staff. I felt bad that after nine months of treatment—with only three months remaining—I hadn't made friends with a single chemo patient. What did this say about me? My turnaround wouldn't be complete, I concluded, until I addressed this.

But I wasn't going to befriend just anyone. It was time to face my greatest adversary. It was time to make friends with Ben.

I put together a plan. I noticed that *Washingtonian* was soliciting nominations for its Excellence in Nursing Awards, so I nominated Mary. I soon received word that Mary had been selected as a finalist and that the winners would be announced at an awards dinner in May. I got Ben's e-mail address from Mary and invited him. He said he'd love to go.

Everything was falling into place. In a single stroke, I could make peace with my nemesis, demonstrate my appreciation for Mary and the rest of the nursing staff, and showcase my new and improved attitude. It was pretty late in the game, but if the night went according to plan, my feat of stagecraft might even be spectacular enough to outdo Ben. I mean, he was certainly a beloved patient, but had he arranged for his primary-care nurse to receive a prestigious award in front of the pillars of Washington's medical community during a fancy dinner? I don't think so.

On May 4, I met my family at the Carnegie Library, in downtown DC, for a cocktail reception before the ceremony. Mary and her husband arrived, and we all got to chatting. Everybody was dressed up. (Dr. Thornton was out of town, but she was there "in spirit.")

Mullins with his family and Mary Cox.

Eventually, Ben walked in with his sister, who had helped him during treatment. We greeted each other warmly. It wasn't long before I was forced to admit that Ben was, as advertised, a pretty amazing guy. He was charming and funny—the kind of person others gravitate to. During the course of our conversation, he told me his cancer story.

About a year earlier, Ben—an avid jogger—had begun to feel unusually winded during his runs. As weeks passed, the shortness of breath intensified and he eventually got himself checked out. Doctors initially thought he had pneumonia, but they soon ordered other tests. That's when they found it: Ewing sarcoma. Stage 4. It had reached the lungs.

I was stunned. I had no idea Ben had it so bad.

Despite the news, Ben had approached cancer the way a member of the Wu-Tang Clan would. He arrived for his first treatment wearing a Patrick Ewing T-shirt—a wisecracking reference to his cancer diagnosis. Over time, the joke evolved—just as the NBA Hall of Famer could never win the big game, Ben believed the disease wouldn't beat him.

Ben is the Washington-area sales rep for the craft-beer maker Brooklyn Brewery—friggin' guy has a cooler job than me, too?—and he continued to work throughout treatment. As it turned out, Ben was even more popular in the hospital than I'd realized. After finishing chemo, he began radiation and made friends with the techs who administered his treatment. One evening they all went out partying at a bar around the corner from the hospital: "We raged," he said.

After cocktail hour, we took our seats in the dining room and the ceremony got under way. My year of treatment was almost over, and I had everything I needed for a buddy-comedy ending. The event had sold out, and there were 230 people in the audience, including leaders from Sibley's nursing department. We were all rooting for Mary.

Ben with his sister Jessy and nurse Mary Cox.

For a time, I felt a pang of guilt about engineering all this. After all, I was a veteran *Washingtonian* staffer with cancer, and everyone at the magazine was pulling for me. It was only natural for this goodwill to influence the award-selection process, perhaps unduly. But I brushed these scruples aside. Mary had kept me alive through some hopeless times—she deserved this.

Finally, the master of ceremonies announced the winner of the award Mary was nominated for:

“Heather Ward of Inova Fairfax Hospital.”

Mary lost. Or really, I lost it for Mary. (I later reread an excerpt of my written nomination, and it really was terrible. Must have been a chemo day.)

The news was deflating. But when the dinner was over, our whole gang headed to a bar down the street. Ben knew all the folks who worked there, and he bought the first round of drinks. We talked and laughed about cancer and chemo and what we'd do when it was over. Everybody was razzing me about my failure to come through for Mary.

It was too bad we didn't win. But everybody, I thought, had a good attitude about it.

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Mary is still working at Sibley's cancer center, and I see her about every six weeks when I go in for blood tests. Dr. Thornton left Washington to become codirector of the sarcoma center at Harvard's Dana-Farber Cancer Institute in Boston. She told me she was quite happy at Sibley, but the offer from Dana-Farber "was like getting a call from the President." She had to take it.

I had my final treatment in late June. My health has slowly improved since then, but my doctor tells me I shouldn't expect my energy to return to pre-chemo levels until sometime next year. In late July, Christina and I drove to Johns Hopkins in Baltimore for my first post-treatment PET scan. It showed no signs of cancer recurrence.

In late September, Ben and I got together at a bar off 14th Street. He told me that upon completing his treatment, he began traveling to Boston every two months to review his progress with Dr. Thornton. The initial signs were positive. The treatment had turned the tumor in his lungs into a mass of dead tissue. He looked fit, and he seemed great.

The reason Ben's attitude was so healthy, I think, was that he could accept that he had no control over his circumstances. He told me he believes that having cancer is "like being stuck in a traffic jam." It's not your fault you ended up there, and you don't know how long it will last. The only thing you can do is turn on the radio and hope the experts clear out the gridlock and get things moving again.

"I'm not good at much," Ben said, "but I'm good at chemotherapy."

I reached out to Ben again a couple of weeks later, just as I was wrapping up this story, to go through some final fact-checking. That's when he told me the bad news: Scans had recently detected two cancer nodules in his lungs. He'd have to do chemo again.

It was a tough break, and Ben admitted he was more scared heading into this next chemo regimen than he'd been before his first. But his body's remarkable resiliency will enable doctors to attack the cancer aggressively. "I'm just going to do it," he told me.

He doesn't know how long the treatment will last or what the exact drug cocktail will be. He's expecting to start soon—but not just yet. First he's flying off to Costa Rica with his new girlfriend.

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Luke Mullins

SENIOR WRITER

Luke Mullins is a senior writer at Washingtonian magazine focusing on the people and institutions that control the city's levers of power. He has written about the Koch Brothers' attempt to take over The Cato Institute, David Gregory's ouster as moderator of NBC's Meet the Press, the collapse of Washington's Metro system, and the conflict that split apart the founders of Politico.

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