

Bert Ranum tells the story of how a move to Florida turned into an odyssey of science, hope, and love as he and his wife confronted his diagnosis with ALS, the disease that had killed his mother and several members of his extended family.

**CLINICAL TRIAL:
An ALS Memoir of Science, Hope, and Love**
By Robert K. Ranum

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CLINICAL TRIAL

An ALS Memoir of Science,
Hope, and Love



Robert K. Ranum

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This book details the author's personal experiences with amyotrophic lateral sclerosis or ALS. The author is not a healthcare provider and the information included in this book is not intended to be medical or healthcare advice.

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Prologue

For an honest person, keeping a secret is like walking with a pebble in your shoe. Depending on its size and location underfoot, it can be either an annoyance or a problem of such mind-consuming proportions that it becomes a disability that forces the person to sit down, take off the shoe, and address the problem. In 2016, Dr. Laura Ranum, Director of the Center for NeuroGenetics at the University of Florida, had a secret that was becoming a disability. The man she loved most in the world and the father of her two children had been diagnosed with amyotrophic lateral sclerosis (ALS), a devastating and fatal neurological disease. That's me. I am Laura's husband. I had been diagnosed with ALS in April 2016, and although Laura's work focused on neurological diseases including ALS, she hadn't told most of the graduate students, post-docs, and other professors in the Center about my diagnosis.

The secret was gnawing away at her. The fact that her husband had ALS had become the motivating force for her work, her creative abilities, and, in many ways, her identity, yet she hadn't told anyone beyond a few close friends. Every interaction at work left her feeling as though she had failed to disclose the issue most relevant to what they were working on.

The diagnosis was just the most recent of many steps that had become progressively more worrisome for Laura. My mother had died of ALS in 1989, the third of her siblings to succumb to the disease. When that happened, Laura was hoping the gene for the disease was recessive, meaning that even if I inherited it, the normal gene from my father would protect me from developing the disease. If, however, the gene were dominant, then it would require only one copy of the gene to cause the disease, and Laura knew that I would have a 50% chance of having inherited that gene and developing ALS. Laura didn't know what the gene was, but her genetics training told her that as long as all of the affected individuals were in one generation, it could be a recessive gene.

That bubble burst with a phone call in about 1995. Laura was in the bedroom when my cousin Marilyn called. Marilyn's mother had also died from ALS, in 1976. Laura picked up the landline phone on the bedside table and, after the pleasantries, Marilyn said, "Margorie's been diagnosed with ALS." Margorie was Marilyn's sister. Laura knew immediately that meant the gene was dominant and therefore threatened me and our two kids. A wave of nausea swept over her, and after the call, she ran to the bathroom and threw up.

Because Laura worked with neurological diseases, she knew what damage they could do to a family. Worry simmered in her for years before reaching a rolling boil when we got the diagnosis in 2016.

Laura decided she needed to tell everyone about the diagnosis at a retreat that the Center for NeuroGenetics had planned for December 2016. The retreat was planned to allow everyone in the Center to get to know each other better and learn about each other's work, and was held at a posh resort hotel on Amelia Island, Florida. A meeting facilitator was present to keep things productive and on track. The group of about 50 or 60 graduate students, post-doctoral students, professors, and clinicians gathered in a hotel conference room to kick off the retreat.

As the Center director, Laura spoke first. She presented PowerPoint slides outlining the goals of the retreat, the Center mission, the expertise of the people in the Center, and the focus of research of the labs. She also described her own background and showed some family photos and then said, "A few of you already know this, but I want you all to know that Bert has been diagnosed with *C9orf72* ALS." She was trying hard to maintain her composure, but tears had already started to fall. "So this work is personal to me." She gave up trying to hold the tears back and continued through sobs. "I plan to do everything within my power to make a difference for Bert and other patients like him."

She was a mess. It had become a catharsis that had been building for years, and through the tears and the struggle to speak in a way that could be understood, she felt some relief from the tightness in her chest. She began to breathe deeply between the sobs, and was able to say, "I

Robert K. Ranum

hope you will join me in this fight against neurological disease.”

Chapter 1:

Florida

The conversation about moving to Florida started when Laura and I were in Costa Rica in January 2009. Laura had organized a scientific conference in San Jose, Costa Rica, and I joined her after the conference for a week of vacation. During a conference dinner one evening before I had arrived, she was chatting with a friend, Dr. Maury Swanson, from the University of Florida. Laura and I grew up, went to college, and had at that time spent our entire lives in Minnesota except for occasional brief vacations or college studies abroad. Like every Minnesotan who escapes in January for a brief but wonderful break from the long, cold, Minnesota winter, she was intoxicated with this new, warm, green paradise and wondering aloud why we lived in a place with such a hostile environment. That prompted Maury to suggest applying for a position at the University of Florida. He said, “We’ve got a position opening up. Why don’t you apply to UF? We’d love to have you.”

At the end of the conference, we left San Jose on a de Havilland Otter, a single-engine prop plane seating about 10 people, operated by Sansa Airlines, and flew to Puerto Jimenez, a small town on Costa Rica’s Osa Peninsula. The peninsula is famous for the Corcovado National Park, known for having a diversity of

biological species not surpassed by a region of similar size anywhere in the world. We landed on a gravel runway just as a goat crossed ahead of the slowing airplane. Our destination was the Bosque del Cabo, an ecotourism resort with luxurious accommodations set amid one of the only old-growth rainforests on the Pacific Coast.

It was a perfect environment for Laura to work on persuading me to consider a move to Florida. The resort is located on a bluff overlooking the Pacific, and the deck of our cabin gave us a wonderful view of blue water far below stretching to the horizon. As we admired the view and watched for Scarlet Macaws and monkeys, the icy bonds that had tied us to that frozen land in the North may have thawed a bit. Still, when Laura mentioned the idea of moving to Florida, I said, “Are you crazy? People go to Florida to die. No one goes there to work.”

I added, “And what would I do? You would have to get a big raise to replace my salary if I left Fredrikson.”

I had at that time been a lawyer at Fredrikson & Byron, P.A., one of the largest law firms in Minnesota, for twenty-six years. I was a business lawyer with a good practice that had allowed us to send our two kids to private schools and now college. I had some good clients in the Minneapolis area and enjoyed my work. A move would put my practice at risk and, from my point of view, just didn't make sense.

I felt a little guilty about that conclusion, however. I had been a bit of an anchor on Laura's career. Many professors move to advance their careers, but Laura had stayed at the University of Minnesota to allow me to pursue my legal career in Minneapolis. She completed her graduate work there, did her post-doctoral studies there, became an assistant professor there, and then finally became a full-tenured professor at the University of Minnesota. She was successful enough to get occasional questions about whether she would consider a move, but she rejected them all because she knew that moving the family would cause too much disruption.

The possibility of a position at the University of Florida was more interesting to Laura than any of the others for several reasons. She already had productive collaborations with several colleagues there and wanted an opportunity to build a broader research program focused on neurogenetics.

Also, the kids were leaving home. Paul was already away at St. Olaf College in Northfield, Minnesota, and Maddie, two years younger, would graduate from high school in the spring and start at St. Olaf in the fall. A move wouldn't disrupt their lives significantly. We had lived in the same house at 2116 Carter Avenue in St. Paul for their entire lives, so at least in Laura's mind, it was time for a change.

When we returned to frozen Minnesota from that trip to Costa Rica, the seed had been planted. But like most

things in the Minnesota winter, it lay dormant for months. When Laura suggested that applying might cause her colleagues at the University of Minnesota to take her less for granted, I thought, *Right, that couldn't hurt*. She worked up an application and sent it in. Maddie didn't like the idea. She said with authority, "Mom, families are like trees. They spread roots. You can't just uproot them and move them to a different state."

I continued to go into the office every day, sit down at my desk, work at my computer, and make and receive telephone calls. But now I observed my day with the possibility of change in my mind. Most of my meetings were internal meetings with other lawyers at Fredrikson about internal firm stuff, not meetings with clients. While they were enjoyable because, after all those years, most of the lawyers at the firm were good friends, it wasn't really important for me to be there. As for client work that actually generated revenue, 90% of that was done by computer and telephone, which I could do, I realized, anywhere.

My most important client, Cardiovascular Systems, Inc. (CSI), held board meetings every quarter that I attended, but the directors flew in for those. Why couldn't I do the same? Even the CEO of CSI lived in California and commuted, as needed, to Minnesota for company business. Although some board members complained about that, they let him get away with it. I began to think it might be possible to stay with Fredrikson & Byron,

move to Florida, and travel back to Minnesota as necessary for meetings.

This idea presented a couple of significant challenges. Each state has its own licensing requirements, and a lawyer who practices law in a state in which he is not licensed is subject to enforcement action for the unauthorized practice of law. Some states, like Florida and California, are more aggressive about enforcing their rules on unauthorized practice of law because they see more lawyers from other states moving there and practicing law without a license. I knew I would have to get licensed in Florida in order to practice law there. And I knew to get a license in Florida, I would have to take and pass the Florida Bar Exam.

The other challenge would be generating new clients in Florida. I generally worked with early-stage companies. This was fun because there is an energy in start-up companies that is often missing in large institutional organizations. I worked directly with the founders or management team, and shared the adventure of each successful fundraising or merger or the excitement of an acquisition that provided a liquidating event for investors. I was a counselor to officers and board members, providing business advice as well as legal advice.

But early-stage companies have a life cycle. Some don't make it and often cease business, sometimes leaving Fredrikson with unpaid legal bills. Others, if they are

successful, get acquired by a larger company that is represented by other legal counsel, and we lose the client. CSI is the rare exception, a long-term client that I had represented since the founder and CEO came to me in 1994. I had represented CSI through its growth from a start-up company (that almost failed with the market turmoil in 2000) to a public company with a market capitalization in excess of \$1 billion. But I knew eventually I would lose CSI as a client also, most likely through an acquisition, I thought then.

Therefore, my continued success as a lawyer required developing new clients. That would be much harder in Florida, where most people would never have heard of Fredrikson & Byron, P.A. In Minnesota, Fredrikson is well known in the business community as one of the top law firms. Clients who hired me knew they were getting a team of top-notch lawyers to work on their matters. I could invite them to visit our impressive offices on the 34th to 40th floors of US Bank Plaza in Minneapolis. In Florida, my business card would have the name of a firm no one had heard of, and I would be working from home, at least at first.

In quiet moments, I thought about what I owed to Laura. Her work, although not as well compensated as mine, was more important. She was breaking new ground in research on neurological diseases, doing work that was one of a kind. I was doing work that could be done by thousands of other lawyers. She deserved more support than the University of Minnesota was giving her. She

had shortchanged her career for me and the kids. Maybe I should take a risk with my career for her.

I also considered my age, 51, and the fact that my mother had died from ALS at age 62. We knew from the pattern of inheritance in my mom's family that there appeared to be a 50% chance that I had inherited the gene that caused mom's ALS and also die early from ALS. This made the risk with the career seem insignificant and strengthened my desire to support Laura in whatever she wanted to do. We had been financially conservative and responsible all our lives and now had more resources to take risk with than ever before. And it might be fun, I thought.

By the time that Laura received an invitation from the University of Florida to come down for interviews, I was willing to move ahead with caution.

Chapter 2:

Gainesville

The recruitment process took a year and half. Laura went for the first visit alone in the summer of 2009 to give a seminar and have a round of interviews. That went well, and so I joined her on the second trip in the fall for additional discussions and interviews. Laura presented her list of terms that she would like to see in an offer letter: a start-up package that would allow her to set up her lab, financing for a new Center for NeuroGenetics that Laura would lead, money for additional recruitments to the Center, and a salary with a nice increase from her University of Minnesota salary.

Laura's second visit was my first time in Gainesville. There is no direct flight from Minneapolis to Gainesville. Delta offers several flights each day from Minneapolis to Atlanta with a travel time of about two hours, but then the Gainesville traveler is required to connect to a flight to Gainesville, almost always on the D concourse of the big Atlanta airport, served by one of Delta's partners operating a smaller plane, with a travel time of about an hour. The lack of a direct flight between Minneapolis and Gainesville extended the travel time significantly. With time in the airports prior to flights and connecting in Atlanta, the trip takes about five hours.

Upon landing, we disembarked into the single waiting area of the Gainesville airport, and after a short walk, we were on the street. I was struck by how small the airport was. I told myself, *Small is good. The less time we waste in airports, the better.* But I worried about the size of the market for lawyers like me.

We stayed at the Hilton Hotel on 34th Street, near the UF campus. While Laura was away at meetings, I went for a run. It was hot. I ran through the campus to get a feel for the place. It was beautiful, with red brick buildings along tree-lined streets with a 20-mile-per-hour speed limit. I ran by Lake Alice and smiled at the exotic sight of a beware of alligator sign. I stopped to marvel at the Baughman Center, a curious chapel on the shores of Lake Alice with a gothic-inspired, modern design, with soaring windows. Eventually, I got to Ben Hill Griffin Stadium, aka “The Swamp.” As a sports fan, I was aware of the storied history of Florida football and the national championships in 2006 and 2008 and felt as though I was in the presence of greatness. I was surprised to see that the stadium was open, and as I cautiously jogged up the ramp, expecting someone to tell me to get lost, I saw that others were running up the steps inside the stadium. After pausing a moment to admire the field and the empty bowl of the great stadium surrounding it, I too ran some steps in the stadium.

On the way back, drenched in sweat, I thought maybe I could make this work. Gainesville was small, but the University of Florida was an impressive place. I

imagined opening a satellite office of Fredrikson & Byron in Gainesville with a few associates. If Laura wanted to come here, I decided, I would work hard to build a practice here.

We came back to Gainesville again in January 2010 to work out the terms of Laura's deal and to look for housing with a real estate agent. At my request, the University set up meetings for me with several leaders in the business community, including David Day, the director of the Office of Technology Licensing, referred to as the OTL. David was 60-something with a full head of well-combed, white hair and an expressive face that he often uses to great comedic effect by matching a serious expression with a hilarious story. I met with him in the OTL office on the UF campus, and he talked about the thriving start-up company environment driven largely by OTL licensing. He described the Innovation Hub, which was planned for construction a few blocks away, and the Sid Martin Biotech Incubator in Alachua, about 10 miles down the road. He said other law firms came in from out of town to work with local companies. He was enthusiastic about the business environment in Gainesville and especially the power of the University OTL to continue to spin off new businesses based on University intellectual property. I walked away from that meeting encouraged about the prospects of getting new clients.

I also met Brian Hutchison at a Starbucks. Brian was the CEO of RTI Biologics, Inc. (now RTI Surgical, Inc.),

one such business started with UF technology and now a public company. Brian was probably 50-something and had the friendly, although somewhat reserved, bearing of someone practiced in dealing with people asking for something. We talked about RTI, the business environment in Gainesville, and neighborhoods. I gave him my pitch on Fredrikson & Byron and how I had decades of experience working with companies like his and that I would be right here in Gainesville and happy to help. He explained that they were currently using Fulbright & Jaworski, a well-known New York law firm, but he would keep me in mind. I thought it was a good meeting but knew it would be hard to replace Fulbright.

As the snow melted in Minnesota, Laura continued to communicate via email and phone with the University of Florida and we talked more seriously about moving. I began to look into preparing for and taking the Florida Bar Exam.

The bar exam threatens every lawyer like Scylla and Charybdis threatened Odysseus. To stretch the simile a bit further, let's imagine Scylla, the six-headed monster, is the Multistate Bar Exam, and Charybdis, the whirlpool, is the Florida-specific portion of the exam. Either one can kill the hero and prevent the safe passage of Odysseus back to Ithaca. Anyone who wants to have a prayer of passing has to spend time preparing to navigate both portions of the test.

The exam is two days. Each day is broken into a morning testing block from 9:30 a.m. to 12:30 p.m. and then an afternoon testing block from 2:15 p.m. to 5:15 p.m. The first day is focused on Florida law and consists of essay questions in the morning and multiple-choice questions in the afternoon. The second day is the Multistate Bar Exam with 100 multiple-choice questions in the morning and 100 multiple-choice questions in the afternoon. The Multistate Bar Exam is developed by the National Conference of Bar Examiners and is used by many states to test understanding of legal concepts and legal reasoning.

It is a mistake to assume that an experienced lawyer like me might have some advantage in taking the bar exam. Lawyers typically specialize in particular areas soon after law school. I became a corporate and securities lawyer, and although I was immersed in the minutiae of securities regulation and Minnesota and Delaware corporate law, I had largely forgotten the real estate, constitutional, civil procedure, torts, and Uniform Commercial Code law I had learned in law school 27 years earlier. And I had no knowledge of Florida law. I was at a disadvantage to all those kids who were fresh from law school, especially Florida law schools, and likely to remember more of that information. I also wondered if at 52 I was as able to study and retain large volumes of information the same way I could at 25.

But the truth is, no one relies on what they learned in law school or in practice to take the bar exam. There is

an entire industry offering to prepare worried bar candidates for the exam. For a fee, bar review courses plot out the studying and practice exams in a systematic way and provide you with books, video lectures, and mnemonics and other memory tricks, which as a whole give you a good chance of passing the bar. They tout their bar passing rates, which often hover around 90%, but everyone fears being in that bottom 10%.

Intelligence is not enough to pass the bar exam. Among those who have failed various state bar exams are Franklin D. Roosevelt, Hillary Clinton, Michele Obama, and John F. Kennedy, Jr. Although those names gave me the comfort of knowing I would be in good company if I failed, I assumed that failure would diminish the amount of respect I had in the eyes of my law partners, many of whom knew I was taking the Florida Bar. It is a stain on the record of any lawyer, and we all want to avoid it if we can.

When it appeared that Laura was likely to work out an acceptable deal with the University of Florida, I signed up for a Kaplan bar review course for Florida. Kaplan offered online lectures on demand, and so I planned to continue working but try to get home early to do the bar review in the late afternoon and evenings. As recommended by Kaplan, I began studying in May for the July exam.

My plan was to get to the office early, by 7:00 or 7:30 a.m., work until 3:00 or 4:00 p.m., and then go home

and study for the bar. I remembered the luxury of studying for the bar after law school when that was all I had to do and it was a full-time job then. I wasn't sure how this was going to work. I soon found that I couldn't get through the full amount of bar review materials designated for each day, even if I stayed up until 11:00 or midnight. I put in extra time on the weekends to catch up and started to go home a little earlier. Soon I was eating breakfast before leaving the house, working at the office until about 1:00, and then taking off for home, where I would grab a bite to eat and start to watch lectures and take notes. I needed about seven or eight hours of sleep, especially with that intense schedule, and so I usually stopped around 11:00 p.m.

Late May through late July was a strange period. I let the compulsive bear in me out of its cage. I stuck to the prescribed schedule. I secretly enjoyed reviewing constitutional law and criminal law again and having all those cases and principles top of mind. I knew I was unlikely ever again to have this breadth of legal knowledge and have memorized so many technical rules. I had trained for the marathon and now it was time to run the race.

We made another trip to Gainesville in June 2010, and Laura accepted UF's offer. It was a good offer including most of what she had asked for. Maddie had concluded that St. Olaf was not for her and was planning to transfer to the University of Pennsylvania in the fall, so she had

conceded that sometimes a move is appropriate and necessary.

The bar exam was July 26 and 27 at the Tampa Bay Convention Center. I flew into Tampa from Minneapolis and reviewed my bar review outlines in the airplane. I checked into a hotel near the Convention Center, decided I had done all I could, and had room service bring up something to eat and turned on the TV.

The next morning, I walked to the convention center and joined the crowd of test-takers milling about. Most of them were in their 20s, and I felt conspicuously old. I scanned the crowd and saw a few others who looked a decade or two over 25. We had to go through a metal detector to gain admittance to the testing area. No cell phones were allowed in the testing area. Most people had brought laptops. I had not. I had gone back and forth about whether to bring a laptop to write the essay portion of the exam and ultimately decided to write it by hand. I had done that the first time I took the bar exam, and I wanted to avoid any last-minute technical issues such as a software glitch or a battery failure or some other problem.

There were thousands of us. The testing center was huge, filled with tables and chairs. Two test takers sat on the same side of each table facing the front of the room. Each of us had been assigned a number, and we found the table corresponding to our number. I was nervous. A proctor at the front of the room gave us

instructions. We were not to open the folder with the questions that were being distributed to each table until he told us to begin. When the time was up, we were to immediately stop typing or writing. A digital clock was visible in the front of the room showing how much time remained.

He announced we could begin. I read the questions briefly, made a mental note of how to allocate the three hours, then read the first question carefully. Recognizing several issues to discuss, I began writing. By the time I started the second question, I wondered whether I had made a mistake in deciding to write by hand instead of using a laptop. I wasn't able to write as fluidly and quickly as I remembered. By the end of the first hour, my hand was getting tired and my handwriting began to deteriorate. I worried about whether the graders would be able to read it. I pressed on.

During the third hour, I started to feel an urge to pee. With my slow handwriting, every minute was important, but so was the need to pee. I fought to maintain focus on answering the question, then looked at the clock and recognized I was going to have to pee before the session ended. So I had no choice. I got up, and though I wanted to run, I forced myself to walk the long walk to the restroom in the corner of the cavernous room. When I returned, I redoubled my efforts at answering the questions and making my hand move as quickly as possible to produce legible handwriting. The

time mercifully expired on the essay portion shortly thereafter.

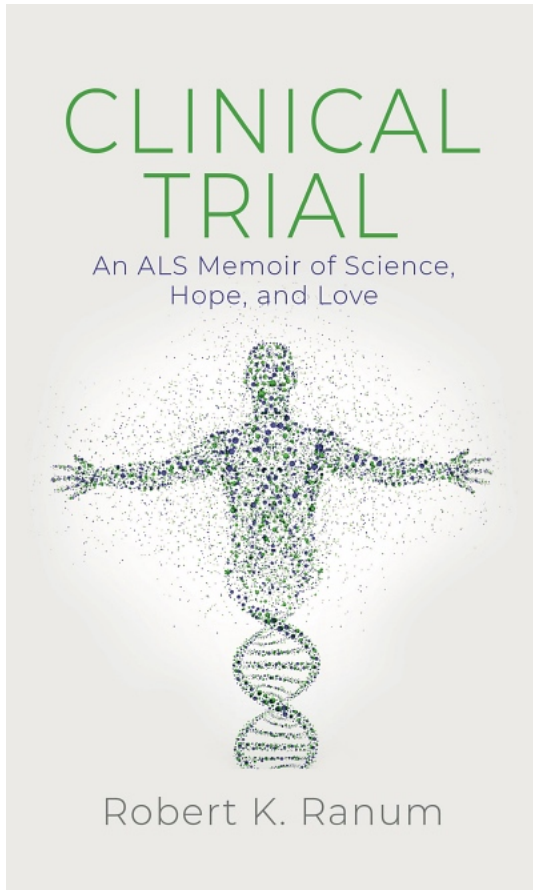
During the exodus for lunch, I tried not to listen to the kids talking about the hidden issue in the third question, or their answer, different than mine, to the second question. I didn't feel bad about my answers, but I didn't feel good either. With tests like these, I knew that my mind tended to gravitate to those areas about which I was uncertain and discounted the stuff I knew cold and could easily discuss. I ate my lunch and steeled myself for the afternoon session. I limited the amount of liquid I drank at lunch and made sure to empty my bladder before the afternoon session.

The afternoon session covered Florida law in a multiple-choice format, so there were no handwriting issues and my precautions to avoid a restroom break were successful. I used all of the three hours and finished most of the exam. In the final minutes, I may have filled in several circles on the answer sheet without reading the questions in the hope of getting one or two correct answers by luck.

The second day was less stressful. I knew the drill, the layout of the place, where the restrooms were, and that I could easily blacken the circles of the answer sheet with my No. 2 pencil. I knew also that the enemy on the multistate bar exam is time and that I would have to move quickly. The three-hour morning and afternoon sessions each contained 100 questions, and we knew

that we had to do about 33 questions per hour and about 17 each half hour. That means that if you spent two minutes on a question, you were going too slow. All that I remember about the multistate exam is trying to maintain focus and read quickly. It is a test of how well you can maintain focus over a three-hour period as well as your knowledge of the law.

I felt hugely relieved when it was over. I called Laura from the hotel room after that second day and said, “I don’t know if I passed, but I gave it my best shot.” The next day I flew to Dallas, where I met Laura and Maddie at the airport. We flew to Costa Rica for a 10-day vacation as a reward for having survived this stage of the odyssey of our move to Florida.



Bert Ranum tells the story of how a move to Florida turned into an odyssey of science, hope, and love as he and his wife confronted his diagnosis with ALS, the disease that had killed his mother and several members of his extended family.

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