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# From Bedside to Bench and Back

Research driven by patients with rare diseases is producing faster discoveries and treatments—and challenging long-held assumptions about knowledge production.

One night in 1995, Tracy Dixon-Salazar and her husband awoke to find their two-year-old daughter, Savannah, rigid and blue, her eyes rolled up into her head. This was the first of thousands of seizures for Savannah, who was finally diagnosed at the age of five with Lennox-Gastaut syndrome, or LGS, a severe form of epilepsy marked by continued seizures and progressive intellectual disability.

As her daughter's condition worsened, Tracy, then a stay-at-home mother who hadn't attended college, started going to the library to read scientific papers about LGS. Intrigued and irritated by the opacity of journal articles, she began taking classes, earning an associate's degree followed by a bachelor's, then a master's, and—12 years into her studies—a PhD in genetics and neuroscience.

By this time, Savannah was averaging 75 seizures per week, was frequently hospitalized, and had suffered brain damage and developmental setbacks. Twenty-six different therapies had failed to help. In 2011, at the suggestion of her postdoc advisor at the University of California San Diego, Tracy sequenced her daughter's genes and eventually discovered a cluster of mutations around a calcium signaling pathway—which immediately reminded her of the particularly terrible seizures Savannah had had during periods when she was taking calcium supplements. Convinced that calcium was a problem, she found a drug approved by the Food and Drug Administration (FDA) used to control high blood pressure that acted on the same calcium signaling pathway. She presented the data to her daughter's pediatric neurologist, who agreed to prescribe it. Within two weeks, Savannah, then 18, experienced a dramatic reduction in her seizures—from 75 to just 3 or 4 per week. Twelve years later, she continues to experience a 90% reduction in seizures.

At an event in Aspen, Colorado, hosted by the Story

Collider, Tracy reflected on her journey: “You really shouldn't have to get a PhD to figure out what's wrong with your kid, and to do the research yourself to find the medicine behind the science, and then convince the physicians to try that. You really shouldn't. But a mom's got to do what a mom's got to do, and patients got to do what they got to do, until science and medicine catch up.”

## Challenging the patient-researcher divide

For most of the past century, scientists and the sick lived in largely separate worlds. Knowledge production was left to a narrow circle of credentialed scientists while patients were recruited to participate as subjects in studies. This traditional, expert-driven research model, reinforced by the growth of large academic medical institutions, meant the road from bench to bedside was long, and it typically ran in only one direction.

That started to change during the 1980s, when patient advocates with HIV/AIDS, and later cancer, began to demand more direct consideration of their needs and priorities. Over the last two decades, the effort has been joined by increasing numbers of patient-led groups seeking treatments for rare diseases.

Despite their name, rare diseases are actually quite common: an estimated 10,000 diseases affect 350 million people globally. Fewer than 5% of them have any FDA-approved treatments. Since so few patients with any given disease are seen at any one institution, rare diseases often fall through the cracks of traditional academic research. In search of diagnoses and treatments, patients and their caregivers have been banding together to drive research forward. Today there are several hundred patient-led rare disease organizations in the United States alone.

This patient- and family-led wave is challenging the research status quo. Rather than asking for a seat at the table, these advocates are setting it, inviting researchers to join their communities, funding research according to their priorities, and bringing unique insights and perspectives that can only come from day-to-day knowledge of the disease.

Since 2019, the Chan Zuckerberg Initiative (CZI), where I work, has committed approximately \$75 million to patient-driven research in rare disease, including directly partnering with 85 patient organizations through the Rare As One project. The media tends to cover rare disease advocates disease by disease, as sentimental one-off stories of determined parents battling their children's terrible and neglected conditions. But as a group they are a growing force, centering the largest stakeholders in medicine—the patients—in shaping and accelerating biomedical research by creating a new dialogue between bedside and bench.

### Launching the Rare As One project

I became increasingly interested in the power of patients over the course of 20 years working in science policy. At the American Civil Liberties Union, where I led an effort to challenge gene patenting, patients played a critical role in articulating the ways that gene patents obstructed access to genetic testing and care. A few years later, while helping to design and launch President Obama's Precision Medicine Initiative, I was inspired by patient leaders who were seeking to reform the siloed US health care system. Doctoral student Steven Keating, for example, printed a 3D model of his brain tumor and collected 75 gigabytes of his medical data to understand his own condition and inspire patients to make their data open source in order to build agency and catalyze research.

My interest was also personal. A few months after I left the Obama administration, my son, then 4 years old, experienced a sudden, explosive onset of seizures. After a 10-day stay in the hospital and three failed therapies, I was told that my son's seizures might be entirely benign, or he might have a potentially severe and rare neurodevelopmental disorder. The only way to know was to take him home to watch and wait. Over the next year, there were more seizures and a few ambulance calls, but to our great relief, eventually his seizures subsided, then stopped altogether. During this time, I was overwhelmed and frustrated by the clunky imprecision and nonsensical inefficiencies of the medical system.

My growing sense that patients hold a key to reforming the country's health system was confirmed a few months later when I met David Fajenbaum, who had made astounding progress in a rare condition called Castleman disease. David was in his third year of

medical school when he was diagnosed with the disease, which threw his immune system into hyperdrive and sent him to intensive care. Between life-threatening relapses, he came to realize that although the disease had been identified in the 1950s, it was little understood because researchers interested in the disease worked in isolation. In 2012, he emailed every researcher who had ever published on the subject to join the Castleman Disease Collaborative Network. The network eventually aligned on a new model for understanding the disease, which led David to identify an underlying mechanism and treatment for his disease that has kept it in remission for more than nine years. This network approach, which now includes more than 1,400 patients, researchers, and clinicians, has since led to the discovery of 10 additional repurposed drugs for Castleman disease and cancer.

David's lightbulb moment illuminated the pervasive role of chance in the way medical research is currently conducted: success depends on the right researcher with the right idea coming along at the right time when the right funding opportunity is available. By contrast, a more rational approach is to build a community of stakeholders (researchers, clinicians, and patients) to evaluate the state of the science in the disease area, identify and prioritize high-impact research questions, and then recruit the most qualified researchers to conduct each study. As I listened to David talk, I wondered: How could we do this for every rare disease?

After I joined CZI in 2018, I set out to identify how the initiative—with its audacious mission to cure, prevent, or manage all disease by the end of the century; its capacities in grantmaking, science, and technology; and its commitment to community-driven solutions—could support and leverage the power of patients to accelerate biomedical research and innovation in rare diseases. Over the course of a year, our initial team of three at CZI met with David and Tracy and dozens of other extraordinary patient advocates—including Josh Sommer of the Chordoma Foundation, Matt Might of NGLY1.org, and Pat Furlong of Parent Project Muscular Dystrophy. They helped us understand the enormous challenges that patient communities face and gave advice on how we might best support them.

Talking with these groups helped us to realize that patients were doing far more than “engaging” as research participants or advocates. They were actively *driving* research forward. They were building strong, highly informed patient communities, recruiting researchers to study their diseases, shaping research questions, building clinical registries, facilitating natural history surveys, developing biobanks, helping to verify disease models, funding clinical research, and partnering with industry in their quest for treatments and cures.

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We also learned that even the most well-organized patient communities face significant barriers. Founding a rare disease foundation was never part of anyone's career plan. And balancing the competing demands of running a small organization and being a caregiver (or seeking care as a patient) is enormously challenging. Moreover, the vast majority of these groups are funded through bake sales and GoFundMe campaigns—so few have the ability to pay staff, never mind fund research. And without shared infrastructure in the form of roadmaps and tools, each group is forced to reinvent the wheel as it goes about building community.

Groups that did manage to raise research dollars typically found themselves having to navigate a complex and bewildering research ecosystem. Some groups, understandably dismayed by the lack of research in their disease area, rushed to launch a request for proposals or fund an individual researcher they encountered rather than taking the time to develop an understanding of the broader disease landscape. Others did painstaking work to set up patient registries to collect information from their community, only to find that the data collected were not useful for supporting the range of research studies that were needed.

In June 2019 we launched CZI's Rare As One project. At its core was an incubator-style program that would fund early-stage, patient-led rare disease organizations as they worked to accelerate research in their disease areas. We believed the communities themselves would have the best ideas for how to overcome the challenges they faced, and hoped that working directly with a subset of groups might point to replicable—even scalable—solutions, as well as opportunities for the groups to learn from one another. In addition, the project would fund organizations seeking to pilot and test tools and approaches for patient-led groups that were unlikely to be funded otherwise.

To launch the incubator, we invited patient-led, 501(c)(3) organizations to apply to join the Rare As One Network. Awardees would receive \$600,000 in funding over three years to build or expand collaborative research networks in their disease areas, convene scientific meetings, and partner with researchers and clinicians to identify knowledge gaps and develop prioritized research agendas in their disease areas.

We initially planned to pilot the network with 10 organizations, but we were so inspired and impressed with

the quality of applications that we ultimately selected 30 awardees out of more than 300 applicants. The vast majority of the organizations were less than five years old, with budgets of less than \$300,000 and all-volunteer staffs. Few were led by individuals with formal scientific training.

We recognized that funding alone was not enough to ensure success. To support and learn alongside these groups, CZI stood up an organizational and scientific capacity-building program, providing groups with monthly trainings and network calls on topics such as finance and operations, hiring, fundraising, strategic planning, and board development. We created a science advising program (which Tracy Dixon-Salazar, who joined us as a consultant, helped to develop), and partnered with the Milken Institute's FasterCures to create a mentorship program. Over the course of the grant cycle, we encouraged the groups to utilize and codevelop tools in partnership with research organizations and tech startups, and we created spaces for the groups to collaborate with one another, including through monthly community calls and an online forum.

The network officially launched in early 2020, just as the COVID-19 pandemic was getting underway. Rare disease patients, many of whom are immunocompromised or otherwise at high risk from infection, were soon deeply affected by delays, long waitlists, and cancellations associated with their medical care. The pandemic also resulted in catastrophic shutdowns for clinical studies and laboratories.

Despite these challenges, by the end of 2022, it was clear that our network organizations were exceeding the terms of their grants. Collectively, the 30 groups had substantively engaged nearly 600 researchers, hosted more than 70 scientific meetings, and developed 26 prioritized research agendas. And beyond this, they had launched 40 registries and biobanks, funded or partnered in 135 research projects, coauthored 60 scientific papers, secured 65 industry partnerships, and began 17 clinical trials, with several more in progress.

But these are all the metrics of scientists. For patients and families, the metrics that matter are changes in people's lives. Although it generally takes on the order of 30 years to go from basic discoveries to FDA-

approved therapies, several groups within the network are compressing the process to less than a decade. For example, just six years after researchers identified mutations in the TANGO2 gene and the TANGO2-related deficiency disorder was discovered, research funded and launched by the TANGO2 Research Foundation revealed—and ultimately confirmed—that one or more components of B vitamins were associated with reduced risks of the most life-threatening disease symptoms. A review of the evidence at the foundation’s scientific conference led to the unanimous approval and publication of nutritional recommendations by a group of nine physicians.

Likewise, in only two years, the Association for Creatine Deficiencies launched a patient registry, natural history study, and gene therapy consortium that led to the development of a gene therapy approach that has proven effective in combating deficiencies in mice. And KIF1A.org,

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founded in 2016 with a community of 10 families, leveraged its grant to bring together a robust community of more than 500 patients and academic and industry partners who are working on multiple therapeutic approaches for KIF1A Associated Neurological Disorder. And one custom-made gene-based therapy is already being tested in a patient.

Early results from patient-led or patient-partnered tools and approaches piloted under the Rare As One project were also promising. The Rare Cancer Research Foundation pioneered a direct-to-patient tissue donation program that enabled 100 rare cancer patients to direct tissues obtained during surgeries to research, which led to the creation of more than 40 cancer research models. I AM ALS launched the Organizing Playbook, a step-by-step guide on how to empower and mobilize a community to accelerate rare disease progress. And a partnership between the Broad Institute’s Rare Genomes Project and 11 of our Rare As One Network grantees formed to codevelop a prevalence estimator tool for rare diseases that yielded actionable insights for the disease communities.

Encouraged and inspired by the progress of our grantees, in 2023 CZI launched a second Rare As One Network cohort, bringing the total number of funded groups to 50. We also funded 10 collaborative research teams that include patient leaders as coinvestigators on the projects to address fundamental questions in rare neurodegenerative and pediatric inflammatory diseases, in partnership with other CZ Science programs. And we issued two dozen additional grants to innovative rare disease organizations and patient-partnered research programs.

Across each of our funding programs, patient groups are proving to be essential partners in the coproduction of knowledge, and their perspective is leading the way to more equitable, meaningful, and efficient research. Yet the prospect of creating 10,000 separate rare disease organizations is daunting and probably unviable. Ensuring that all rare disease patients have a voice will ultimately require a fundamental realignment of research priorities and approaches to better mirror patients’ interests and needs. To echo Tracy Dixon-Salazar, the burden of accelerating treatments in rare disease cannot, and should not, fall on patients and their caregivers and families.

### **How patients moved from outside research to inside**

Advocacy groups within the HIV/AIDS movement were among the first to challenge the power dynamics of medical research. In the 1980s and ’90s, these activists came into direct conflict with the medical research establishment as they protested, organized civil disobedience, and launched media campaigns to demand greater attention for the growing epidemic, access to experimental drugs, and a voice in advancing research.

Over time, this adversarial relationship became an effective collaboration toward a common goal of identifying effective treatments for HIV/AIDS. Unlike traditional advocacy groups that exerted pressure from the outside, HIV/AIDS patients sought to actively drive research from the inside. The movement is credited with directly influencing the research agenda, securing research funding, changing clinical trial practices, accelerating drug development, and expanding access to experimental interventions. HIV/AIDS activists became persuasive research critics and credible collaborators. In the process, they demonstrated that scientific research does not take place in isolation but is inextricably linked to societal values, such as equity and trust, and social structures, such as building patient registries and enrolling patients in clinical trials.

Encouraged by the effectiveness of this strategy, breast cancer advocacy groups then demanded a voice in how breast cancer was characterized and treated. In 1993, advocacy groups succeeded in securing \$210 million from the Department of Defense’s budget for a new breast cancer

research program and were able to carve out a clear role for patients to participate in shaping the new program's research goals.

By the late 1990s, the Cystic Fibrosis Foundation (CFF), initially established in the 1950s by a small group of parents, was seeing results from decades of investment in patient registries and research into the disease. The CFF began funding research and investment in early-stage drug discovery and development, which has now led to more than a dozen new CF treatments and helped expand the lifespan of many CF patients.

Globally, a wide array of patient groups have followed in these footsteps, bolstered by the rise of the internet and social media. Many patients who had been isolated were empowered to build online communities and use these platforms to engage in storytelling and raise funds to direct research projects of their choosing.

This swell of patient voices helped to bring about the creation of new federal programs that embraced the importance of patient engagement in research, including the Patient-Centered Outcomes Research

of the outbreak, thousands of COVID-19 survivors began describing a rolling suite of “long hauler” symptoms, including severe fatigue, brain fog, and breathing difficulties. Congress moved relatively quickly to set aside \$1.15 billion to study this emerging problem, but biomedical research was slow to respond. The first study to characterize long COVID was driven not by an academic research institution, but by the Patient-Led Research Collaborative, a nonprofit, then all-volunteer organization started by long COVID patients who were also researchers.

### **Research with patients at the center**

What would it look like if, to echo Tracy Dixon-Salazar again, science and medicine “caught up” to patients? Over the past three and a half years of engaging with our Rare As One project grantees, we’ve gotten glimpses of just how patient groups, given the opportunity to lead, can change the way medical knowledge is produced and applied. While we’re still in early days, it’s possible to imagine a future ecosystem built around patients and their experiences and directed in a more laser-like way toward treatments and cures.

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Institute, a nonprofit that was established as part of the 2010 Affordable Care Act to promote research aimed at improving the quality of health care in the United States. In 2013, the Rare Diseases Clinical Research Network was created at the National Institutes of Health’s National Center for Advancing Translational Services to advance the diagnosis, management, and treatment of rare diseases. Among the unique features of the program was a requirement that each consortium funded as part of the network include patient advocacy groups as research partners. Today, the network supports 20 rare disease consortia with 190 affiliated patient advocacy groups.

Despite these successes, the last 50 years of patient advocacy have not succeeded in bringing about systemic change in the way knowledge is produced. The concept of engagement is widely referenced but poorly defined; it is often tokenistic and the process remains largely extractive, driven by institutional incentives to build repositories of patient data and samples that can be mined for disease insights.

The resistance of the biomedical research community to patient-led partnerships was made painfully clear during the COVID-19 pandemic. Within six months

A common misconception is that patient-led organizations cannot be relied upon as substantive research partners for two primary reasons: insufficient organizational capacity and passion without scientific rigor. But we have observed instead that even nascent organizations can have remarkable impact with baseline seed funding and the ability to hire one or two paid, full-time staff. And with appropriate training and support, patient groups can gain solid footing to engage as effective research partners and accelerate research by galvanizing collaboration and building research assets. While long-term sustainability is a challenge for many nonprofit organizations, we’re seeing that our grantees have been able to leverage CZI’s support to raise significant follow-on funds. For example, the Association for Creatine Disease increased its budget by more than 500% over the course of its three-year grant. And the Castleman Disease Collaborative Network was able to leverage CZI’s funding to raise an additional \$6.15 million in funding to support Castleman disease research.

As for passion, it is certainly true that patient group founders are often on a deeply personal quest. Their commitment and motivation is unparalleled, and while this can lead to difficulties delegating tasks and creating a cohesive



group, when groups align behind a strategy, it's precisely that passion that accomplishes feats that would not otherwise happen. It took Kim Nye 10 years of searching to finally obtain a diagnosis of SLC13A5 epilepsy for her two children. A year later, she founded the TESS Research Foundation. Over the course of the last 8 years, the foundation has identified and brought together 130 patients from 25 countries, hosted 7 research conferences, secured more than \$10 million in research funding, led the development of treatment guidelines, funded the creation of 15 cell lines and disease models, and partnered with researchers and a biotech company. The foundation is now poised to begin clinical trials of a gene replacement therapy. Says Kim, "I don't think a family like mine could go from disease discovery to potential disease modifying therapy in a few years without the passion and urgency of the patient voice."

Scientists sometimes worry that patient groups, eager to identify pathways to new treatments, may embrace disease therapies or interventions too quickly that are ultimately discredited, or may not fully appreciate the

Patient groups are reinventing the tools of research to be more accessible and more scalable. Most rare diseases lack natural history studies, which provide critical information on the clinical presentation and progression of diseases and are foundational for facilitating drug development. These studies require a critical mass of 50–100 patients, are traditionally done in clinical settings, take a decade or more to amass data, and are prohibitively expensive. Wanting to quickly build a natural history survey from patients who were dispersed around the world, the FOXG1 Research Foundation partnered with the company Ciitizen to use machine learning to extract data from years of medical records. They were able to compile a detailed natural history study of 100 patients in two years at a fraction of the cost, and the approach has been quickly scaled to 50 rare neurological conditions.

Patient groups are also shifting the research landscape in their approach to data and research assets. Patients' interests are fundamentally different from those of institutions or companies; they want their data available to as many groups as possible to encourage progress. When a patient community works with an individual researcher to collect biospecimens

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importance of basic science research and standards of scientific quality. But we have found that patient advocates are eager to acquire scientific and medical knowledge and have a vested interest in ensuring that the science they support with their limited resources is robust, and in fact provide an important counterweight to the myriad influences on research directions, including funding streams and professional pressures. In addition, the patients' perspective and insights may offer an essential addition to the science.

We've also seen researchers themselves become deeply affected by the experience of adopting the rhythms, power dynamics, and end points of research that are centered on patients. Samantha Baxter, a genetic counselor at the Broad Institute who leads the Genetic Prevalence Study, explained that creating partnerships with Rare As One Network organizations has fundamentally changed her understanding of her job. "Everyone we interacted with brought a unique perspective and lens to the project. Their keen insights and informed questions not only enhanced the study results for their own diseases, but shaped how we think about genetic prevalence for all rare diseases."

for research purposes that are stored at a research institution, they risk losing access if their researcher moves. Likewise, when gene therapy programs get dropped or deprioritized, the assets don't revert to the patient community unless that is established as part of a collaborative agreement. Our grantees are actively working to reconcile challenges around control of and access to these prized resources. Optimizing patient-led research will require developing resources and templates for structuring collaborative agreements among patient communities, universities, and industry partners that preserve and protect patients' interests.

Patient groups are also redefining what it means to be a "participant" in research by engaging patients as valuable partners, building trust, and meeting patients where they are. For example, in Puerto Rico, where there is a high incidence of Hermansky-Pudlak syndrome, the HPS Network sends mail to families who don't have access to the internet, organizes school buses and vans to pick up affected individuals and take them to conferences, and continues in-person outreach after hurricanes to ensure no one is left behind. This whole-person, whole-family approach is something the rest of the medical research system could learn from.

## Lofty goals of curing, managing, and preventing disease cannot be met by continuing to do research with the traditional siloed methods of the last century.

One of the great promises of a patient-driven medical research ecosystem is that it could be cheaper, faster, and more responsive to people's differences and needs. We've observed our network groups crowdsourcing experiences and assessments of registry platforms, sharing strategies for holding patient-focused drug development meetings with the FDA, informing clinical guidelines, and navigating processes for developing an International Classification of Diseases code or adding their disease to newborn screening panels. In the future, this process of collective learning will continue as groups engage in a virtuous circle of mentoring and sharing with one another, opening up the way for those who follow.

But as we've gone down this path, it's become clear that the compounded inequities within the experience of rare disease caretaking, research, and advocacy cannot be ignored. Rare disease patients typically undergo prolonged diagnostic journeys of five to eight years, and those timelines are even longer for people underserved by the health care system. Diagnosis opens the door to research and sometimes treatment opportunities, but these too are less accessible to rural, poor, and racially marginalized populations. And running a 501(c)(3) organization on top of caring for a loved one with a rare disease (or having a rare disease) requires time, social connections, financial resources, and education that is simply out of reach for most people.

### Unleashing the true power of patients

Our Rare As One project grantees show the extraordinary potential of patient-led research to accelerate progress in rare disease. Nonetheless, CZI has supported fewer than 100 rare disease organizations, and while its total investment to date of \$75 million in patient-driven research is significant, it's still a drop in the bucket considering the scope of the problems at hand. Unleashing the power of patients to accelerate research will require the commitment of a broad array of stakeholders, and ultimately, the federal government.

Only the federal government can address the systemic inequities of the rare disease landscape in the United States, beginning with diagnosis. The outdated and piecemeal newborn screening program should be revamped to enable screening for many more rare and genetic conditions, starting with the 250 conditions included in the GUARDIAN research study being conducted in New York

City. This would ensure that all newborns are given a chance to live a healthier life. Clinical whole genome sequencing should be integrated into care for rare disease patients, beginning with infants and children in neonatal and pediatric intensive care units. A pilot study demonstrated that testing critically ill infants saved medical costs and led to diagnoses in more than 43% of cases and changed medical care for more than 3 in 10 babies in the study.

The federal government can amplify the effort to move patient engagement out of the "nice to have" category and into a realm where it is seen as essential for accelerating progress against disease. The Rare Disease Clinical Research Network has proven to be highly productive and is an important start; a 2016 study reported that partnership with patient communities has been critical to the success and scientific productivity of the program. Funders should go beyond requiring patient communities to be consulted or included in research proposals. Patient leaders should be engaged as coinvestigators on projects, where appropriate, and compensated and supported as research partners for their time and expertise.

Similarly, funders of biomedical research must create infrastructure to support patient-driven research. This should include platforms to enable patient communities to collect, share, and steward data; legal resources to assist groups in negotiating terms of agreement with research partners in academia and industry; and tools to enable patient organizations to participate fully in the research process.

Finally, the fate of biomedical research should not be left to serendipity. Decisionmakers should ask networks of researchers, clinicians, and patient advocates to collaborate on prioritized research agendas for many diseases—not just rare ones—to guide investment and research. Ambitious goals of curing, managing, and preventing disease cannot be met by continuing to do research with the traditional siloed methods of the last century.

Patient communities are paving the way to a better system and will continue to do so. But public and private institutions must do more to address the systemic inequities that are undermining patients' power to accelerate research. It's time to fully acknowledge and embrace patients as central stakeholders in the research ecosystem—and to realign research priorities around the bedside rather than the bench.

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