CASE STUDY: HEALTHTREE FOUNDATION

“TOGETHER WE CARE, TOGETHER WE CURE”

Turning a Diagnosis into Infrastructure

How HealthTree Foundation built a complete, patient-owned personal health record — and how HealthKey.ai helped HealthTree Foundation make cancer data work for the patient and for researchers

A nonprofit innovation story spanning 2010 – 2026

From a single myeloma patient to 14,000+ patients and 65,000+ research participants

2012	**14,000+**	**7,900+**	**65,000+**
FOUNDED	PATIENTS IN CURE HUB	HOSPITALS CONNECTED	RESEARCH PARTICIPANTS

Executive Summary

HealthTree Foundation is a global nonprofit that exists to help people with blood cancer live longer and better — and to accelerate the search for a cure. It began in 2010 with a single patient: Jenny Ahlstrom, a 43-year-old mother of six, diagnosed with multiple myeloma and given a prognosis measured in a few short years.

Rather than accept that the data needed to fight her disease was scattered, locked away, and inaccessible, Jenny and her husband Paul decided to treat the diagnosis like a startup problem. The result, formally founded in 2012, is HealthTree Foundation and its flagship platform, HealthTree Cure Hub — the only tool that invites patients to contribute their complete, real-world health data to academic research while getting tools to navigate their own care in return.

At the center of that platform is a structured Personal Health Record (PHR): a single, longitudinal, patient-owned record assembled from fragments scattered across every hospital a patient has ever visited. This case study describes how that record came to exist, why HealthTree partnered with HealthKey.ai to build the technology underneath it, and what the PHR now powers on behalf of patients — from clinical trial matching and treatment-option ranking to the Twin Machine and large-scale clinical research.

> *“I wish this had existed when I was first diagnosed, that I didn’t have to build it.”*
> *— Jenny Ahlstrom, Founder, HealthTree Foundation*

The Problem: A Patient’s Data Belonged to Everyone Except the Patient

A diagnosis with no time to wait

In 2010, while the Ahlstrom family was living in Mexico, Jenny was diagnosed with multiple myeloma — a relatively rare blood cancer that typically strikes patients in their seventies. She was 43. At the time, the five-year median survival for the disease was roughly 50 percent, and Jenny’s specific high-risk genetic features put her individual prognosis closer to two years.

She underwent tandem stem cell transplants, traveled thousands of miles for treatment, and spent months away from her family. But the experience exposed a deeper, systemic failure that had nothing to do with any single hospital or doctor.

The data problem

The Ahlstroms had already watched this failure play out once before. Paul’s brother David had been diagnosed with acute myeloid leukemia six years earlier and lived only a year. During his care, David tried an off-label drug that bought him six additional months — but **that information was effectively lost to every other patient in the world.** The same drug was formally approved for his indication fourteen years later. That is how slowly knowledge moves when it is trapped inside individual cases.

For a patient actively fighting a terminal disease, the data problem has three faces:

- **Fragmentation.** As Jenny describes it, every hospital holds only "little bits and pieces" of a patient's history. No one institution — and critically, not the patient — holds the complete picture.
- **Inertia.** A patient's health data sits idle inside a hospital's online chart, helping neither the patient, their doctor, nor the research community find a cure.
- **Trust.** Many technology companies had asked patients to hand over their health data with a vague promise to "do something cool with it later." For patients, that is a massive trust problem — and a non-starter.

> *"Having cancer is like playing chess with your life, and you just don't want to make a wrong move."* *— Jenny Ahlstrom*

Every move in that chess game — which treatment, in which sequence, at what time — depends on information. And the information existed. It was simply scattered, siloed, and unavailable to the one person whose life depended on it.

The Insight: Treat the Diagnosis Like a Startup

Paul Ahlstrom is a serial entrepreneur who had spent his career building companies and, at the time of Jenny's diagnosis, helping create a venture capital industry in Mexico. Jenny had a technology background of her own from her years at IBM. Somewhere in the chaos of treatment, they made a decision that would define the next decade and a half: they would approach the cancer diagnosis the way they would approach a startup.

That reframing produced a specific, testable hypothesis. If the powerful, real-world experience of every myeloma patient could be aggregated into one place, that collective knowledge — not any single trial — could become the fastest engine for research. The missing ingredient was not data. It was a trusted way to assemble it.

The hypothesis

Jenny and Paul believed that **if they built the right tool, and invited a community of patients they had earned the trust of to participate, those patients would contribute their data.** Earlier efforts had failed because they led with the data grab and treated trust as an afterthought. HealthTree inverted the order.

Two design principles fell directly out of that hypothesis, and they remain non-negotiable today:

- **The patient owns the data.** Information contributed to HealthTree remains anonymized, secure, and entirely under the patient's control.
- **The data is never sold.** HealthTree does not sell patient data or information. Doing so would destroy the very trust the model depends on.

Earning trust by being patients

In 2018, HealthTree took the hypothesis on the road with a 50-city tour, sitting down with more than 860 myeloma patients and a prototype of the tool. The Ahlstrom's and their six children sat beside elderly patients and helped them enter their own data, watching in real time where the barriers were.

The patients' questions were consistent: Who are you? Why are you doing this? What will you do with my data? HealthTree could answer all three credibly for one reason — the people building it were myeloma patients themselves, doing it to accelerate a cure. That authenticity is the foundation the entire data model is built on.

> *"A lot of tech companies said, 'Give us all your health data and we will do something cool with it later.' But that's a massive trust issue." — Jenny Ahlstrom*

Building the Personal Health Record

The tool that emerged from the 50-city tour and the years of iteration that followed became HealthTree Cure Hub. And the heart of Cure Hub is the Personal Health Record — a complete, longitudinal, patient-owned record of a person’s cancer journey.

From fragments to a single record

The PHR is built by doing the hard, unglamorous work that no individual patient could do alone. HealthTree pulls a patient’s scattered records together, connects them, cleans them up, and structures them into one coherent profile. A patient can securely link records from multiple care centers — HealthTree today integrates data from more than 7,900 hospitals, including major institutions such as Huntsman Cancer Institute, Dana-Farber, Mayo Clinic, MD Anderson, and Memorial Sloan Kettering.

The outcome is something a patient has almost never had before: a single, comprehensive health record they actually own and can act on. They can track their labs, see out-of-range values at a glance, and generate a health summary to share for a second opinion — with no spreadsheets and no stress.

Why a structured record changes everything

A pile of PDFs is not a usable record. The breakthrough of the PHR is that the data is **structured** — organized consistently enough that software can reason over it. Once a patient’s history exists as structured data rather than scattered documents, the same record can quietly power a whole suite of services on the patient’s behalf. One record; many tools.

The principle: assemble the record once, correctly, and every downstream service becomes possible.

The HealthKey.ai Partnership: The Technology Layer

Assembling a clean, structured, interoperable health record from thousands of incompatible hospital systems is a serious engineering problem. Records arrive in different formats, with different standards, different completeness, and different terminology. Turning that into a single trustworthy profile — reliably, at scale, for tens of thousands of patients — requires dedicated infrastructure.

To meet that need, HealthTree Foundation partnered with HealthKey.ai, which provides the backend technology that powers the Cure Hub platform. The partnership reflects a deliberate division of labor, and understanding that division is key to understanding how HealthTree works.

Two layers, one mission

Layer	Role
HealthTree Foundation	The trust and community layer. A 501(c)(3) nonprofit that holds the relationship with patients, earns and keeps their trust, educates and supports them, and connects them to research. This is the layer patients see and believe in.
HealthKey.ai	The infrastructure layer. The backend technology that ingests fragmented records, processes and standardizes them, and turns them into the clean, structured PHR. This is the engine that makes the patient-facing promise deliverable at scale.

The two are symbiotic but distinct. HealthTree is the trusted, mission-driven home patients come to; HealthKey.ai is the technical foundation that ingests data, resolves it against healthcare data standards, and produces a record reliable enough to make clinical decisions around. Because the heavy infrastructure lives in a dedicated technology layer, HealthTree the nonprofit can stay focused on what it does best: patients, education, community, and research.

What this unlocks

With HealthKey.ai providing the technology backbone, work that once took clinicians hours — assembling, reconciling, and interpreting a patient’s scattered history — can now take minutes. As Dr. Douglas Sborov of Huntsman Cancer Institute has observed of HealthTree’s approach, the organization has been able to do something many academic centers only dream of: amass real-world data and actually make sense of it.

> *“They’ve been able to do some things that many academic centers only dream of, which is they’re able to amass data and make sense of the data.” — Dr. Douglas Sborov, Huntsman Cancer Institute*

What the PHR Powers for Patients

The Personal Health Record is not the product — it is the foundation. Because the record is complete and structured, it can quietly drive a suite of services that each would have been impossible on a pile of disconnected documents. Every service below runs on the same underlying PHR.

1. Treatment Option Matching

Cure Hub shows a patient personalized treatment options based on their own health profile — their stage of disease, their prior treatments, their disease characteristics. The options are ranked in the order myeloma experts would potentially consider them, using decision logic built on the back end with the help of myeloma specialists. A patient can explore those options from home and bring them to their doctor so the two can choose a path together.

2. Clinical Trial Matching

Clinical trial matching is one of the clearest demonstrations of the PHR's value. Instead of facing a list of hundreds of trials with no way to know which apply, a patient sees only the trials they are **personally eligible to join** — the technology compares the structured PHR against trial eligibility criteria. As Jenny describes it, instead of 450 undifferentiated trials, a patient might see 30 or 50 that are genuinely relevant. After a match is found, HealthTree's team helps the patient actually enroll.

3. The Twin Machine — Connecting to Cancer "Twins"

The Twin Machine uses the structured PHR to connect a patient with other patients whose cancer history closely resembles their own — similar past treatments, similar genetics, similar disease course. Patients can see what treatments worked for their "twins," add them as friends, and chat anonymously. It turns the collective real-world experience of the community into personal, navigable guidance — exactly the knowledge that was lost when Paul's brother tried his off-label drug alone.

4. Side Effect Solutions

Cancer brings side effects — from the disease and from the medications used to treat it. HealthTree aggregates patient-reported outcomes so a patient can see what others actually experienced and what helped. The community-based tool can report, for example, that a given number of patients tried a particular solution and how often it helped, and patients can contribute what worked for them in turn.

5. Powering Clinical Research

Finally, the same PHR — anonymized and contributed with the patient's consent — is what makes HealthTree's research model possible. HealthTree Cure Hub is the only tool that invites patients to contribute their complete real-world data to academic research. A built-in researcher portal lets academic investigators post surveys and studies, develop new hypotheses, and access rich real-world data in faster and far less expensive ways.

The speed advantage is dramatic. In one early pilot — a COVID-19 study — HealthTree recruited 1,100 patients in four weeks, a pace that is, in Jenny's words, shocking for any academic study, let alone one in a rare disease. For patients playing "beat the clock" with a terminal illness, that compression of research timelines is the entire point.

One Personal Health Record. Five services. The record is built once; the patient benefits everywhere.

Services at a glance

Service	What it does for the patient
Treatment Options	Personalized, expert-ranked treatment options based on the patient's own profile.
Clinical Trial Finder	Surfaces only the trials a patient is personally eligible for; team support to enroll.
Twin Machine	Connects patients to disease "twins" to learn what worked for similar cases.
Side Effect Solutions	Crowdsourced, patient-reported solutions for disease and treatment side effects.
Accelerate Research	Anonymized real-world data powers fast, lower-cost academic research.

Impact: From One Patient to a Global Community

What began as one family’s response to a diagnosis has become a global nonprofit serving tens of thousands of blood cancer patients and accelerating research worldwide. The numbers below reflect HealthTree’s reach and its research engine.

14,000+	PATIENTS TRUST CURE HUB
9,200+	SEARCHED TREATMENTS & TRIALS
1,300+	SIDE-EFFECT SOLUTIONS
65,000+	RESEARCH PARTICIPANTS
76+	SURVEYS & STUDIES COMPLETED
78	INVESTIGATORS INCLUDED

The research speed advantage

The structured-data model does not just make research possible — it makes it fast. HealthTree reports an average recruitment time of just four to six weeks for its real-world-data studies, with full projects completing in roughly nine to eighteen months. For diseases where patients are racing the clock, compressing research timelines from years to months is a direct contribution to survival.

Impact on the founder

HealthTree’s model is also validated by Jenny’s own outcome. Fifteen years after a diagnosis that gave her roughly two years, she has no evidence of active cancer — in remission for more than four years following CAR-T cell therapy, an immunotherapy that re-engineers a patient’s own immune cells to attack the cancer. It is precisely the kind of advanced treatment that a complete, well-navigated health record helps patients discover.

> *“I could never have imagined what we have built. Just the creation that came out of this terrible situation — it’s become a blessing instead of a curse in my life.” — Jenny Ahlstrom*

Where We Are Going

HealthTree is not stopping at multiple myeloma. The same architecture — a trusted nonprofit relationship layer on top of a HealthKey.ai-powered data and infrastructure layer — is being extended to additional blood cancers, to solid tumor cancers, and toward other terminal diseases. The platform now reaches patients worldwide, and the model is intentionally disease-agnostic: wherever fragmented patient data is keeping people from better outcomes, the same approach applies.

The long-term vision is a future of more effective and personalized cures, in which every patient owns a complete, trusted, interoperable health record — and in which that record works as hard for the patient, and for research, as it possibly can.

Key Takeaways

- **Start with trust, not data.** HealthTree succeeded where others failed because patients — building for patients — earned the right to aggregate data before asking for it.
- **The Personal Health Record is the foundation.** Assembling one complete, structured, patient-owned record from thousands of fragmented sources is the hard problem; solving it once makes every downstream service possible.
- **Separate the trust layer from the technology layer.** HealthTree Foundation holds the patient relationship; HealthKey.ai provides the backend infrastructure. The division lets each do what it does best.
- **Structured data turns a record into a platform.** Because the PHR is structured, it can power treatment matching, trial matching, the Twin Machine, side-effect solutions, and research — all from one record.
- **Patient ownership is permanent.** Data stays anonymized, secure, under the patient's control, and is never sold. That commitment is what keeps the entire model viable.
- **Faster research saves lives.** Recruitment in weeks instead of years means patients racing terminal diseases benefit from discoveries sooner.

Sources & Further Reading

HealthTree Foundation — Our Story & Cure Hub
HealthTree Cure Hub for Multiple Myeloma
KUTV 2News — "Utah cancer survivor creates AI platform to help patients find life-saving treatments" (2026)
Deseret News — "How a cancer survivor turned a bad diagnosis into life-changing work" (2021)
Additional coverage: WHYY, BBC StoryWorks (GSK Target the Future), and CureToday.

HealthTree Foundation is a qualified 501(c)(3) tax-exempt organization. — Together We Care. Together We Cure.