

# Be The Match Helps Patients More Easily Find and Join Relevant Trials

## Be The Match Jason Carter CTSS Uses CTTI's AACT Database

### SUMMARY

[Be The Match](#), a non-profit organization that delivers life-saving blood stem cell therapy to patients in need, launched [Jason Carter Clinical Trials Search and Support \(CTSS\)](#) to help patients with blood cancers or blood disorders and their loved ones find and participate in relevant trials. CTTI's [Aggregate Analysis of ClinicalTrials.gov \(AACT\) Database](#) was foundational to the development of the CTSS.

### GOAL(S)

For many people with blood cancers or blood disorders, treatment through clinical trials provides hope and a potential cure. But it's not always easy to find these trials. Jason Carter, who lived with leukemia for four and a half years before passing away at the age of 28, understood this challenge more than most. He wanted to participate in trials to give himself the best chance for a cure, but he and his family struggled to find enrolling trials on ClinicalTrials.gov. They eventually identified two trials, but it was a cumbersome research process. After Jason passed away, his parents, Bob and Diana Carter, gave Be The Match a generous donation to build a program that removes this barrier for families and helps them locate relevant and enrolling trials for blood cancer or blood disorders through a patient-friendly clinical trial search tool and one-on-one support with a clinical trials navigator.

### CHALLENGES

[ClinicalTrials.gov](#), a registry of clinical trials run by the National Library of Medicine and the National Institutes of Health, provides information regarding characteristics of past, current, and planned clinical studies; in addition, registry data are available for bulk download. However, issues related to data structure, nomenclature, and changes in data collection over time make aggregate analysis by clinical specialty challenging in ClinicalTrials.gov. To bring CTSS to life, Be the Match needed a tool for aggregate analysis of the studies listed in ClinicalTrials.gov related to blood cancer or blood disorders, and they needed the updated information on a regular basis. From there, they could rewrite the study descriptions in plain, patient-friendly language and make it available to anyone via an online search tool.

### SOLUTION(S)

AACT is a publicly available relational database developed by CTTI that contains all information (protocol and result data elements) about every study registered in ClinicalTrials.gov. Content is downloaded from ClinicalTrials.gov daily and loaded into AACT, allowing users to quickly access the aggregate data that is difficult to assemble in ClinicalTrials.gov. AACT offers daily database refreshes, cloud-accessible database outputs, and source code available via [Github](#). For CTSS, AACT would serve as a foundational tool, providing the aggregate, clinically specific information needed to develop the trial finder.

### TAKING ACTION

The team building CTSS first worked to establish criteria for its tool. For example, they only wanted the search tool to show clinical trials for blood cancers, blood disorders, or blood or marrow transplants. Trials could be in phase 1, 2, or 3, but should be interventional studies with sites in the U.S., and open for recruitment. With AACT as the foundation for aggregate outputs of these studies, the CTSS team worked with a vendor to set up a process so that every night, refreshed clinical trial information meeting these criteria is pulled from the AACT Database and sent to the CTSS development team. These updates on new trials are sent via daily emails to the CTSS staff, who then write a plain language summary of the trial and upload it to the CTSS website in a searchable format. AACT also plays an important role in identifying changes to trials already listed on the CTSS website. For example, when the AACT Database is updated to show that a trial has closed, that trial is automatically deleted from the CTSS search tool, so users never have to worry that they will find an outdated study. Likewise, if a study status has changed in AACT from closed to open again for recruitment, or if the intervention, description, phase or age changes for a trial, the CTSS team is notified and updates their site.

### IMPACT

Be The Match actively tracks the impact of CTSS. In 2019, their goal was around building the number of unique contacts to the program, and in 2020, the goal is around the number of contacts who join clinical trials. As of this writing, CTSS has helped 100 people find and join trials in their fiscal year 2020. Be The Match also reports that there is a lot of demand for the program, with new patients and families reaching out daily.

### ADVICE

The CTSS took longer than the team expected to get ramped up, so the CTSS team advises others in a similar position to give themselves time. There are currently approximately 1,200 trials on the site, and even with the help of a contractor, that process took six to eight months. It was a lot of work in the beginning to figure out what the style of writing was for trial descriptions, deciding how to make the templates adaptable and flexible, but also ensure consistency across the trial descriptions. The CTSS development team got feedback from patients and caregivers, and they advise others developing a similar tool to implement such feedback as early in the process as possible. "I don't know how we would have been able to create this search tool if the AACT system was not in place," said one employee on the development team for CTSS. "It was a huge exhale for us when we learned we didn't have to do this all on our own." The hard work was well worth the effort. The CTSS team now serves as a resource for patients and their families who, like Jason Carter, are eager to participate in research to give themselves the best chance of beating their condition. "Families who have used the CTSS tell us this tool has been invaluable," said one CTSS employee. "We are thrilled that we have delivered on our goal, and we aspire to keep improving it year after year."

### ORGANIZATION

Be The Match Jason Carter Clinical Trials Search and Support

**CONTACT**

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**ORGANIZATION TYPE**

Patient

**IMPLEMENTATION DATE**

2017

**TOPIC**

Quality

**RELATED CTTI PROJECT**

[Aggregate Analysis of ClinicalTrials.gov \(AACT\)](#)

**CTTI RESOURCES**

The database for aggregate analysis of [clinicaltrials.gov](#) (AACT) and subsequent regrouping by clinical specialty