Please note: This is a draft of your entry and is only visible to you. You may return to edit this draft at any time from the main challenge page. Once you have finished and are ready to submit your final entry, click the "Submit entry" button to submit it for judging.

Preview

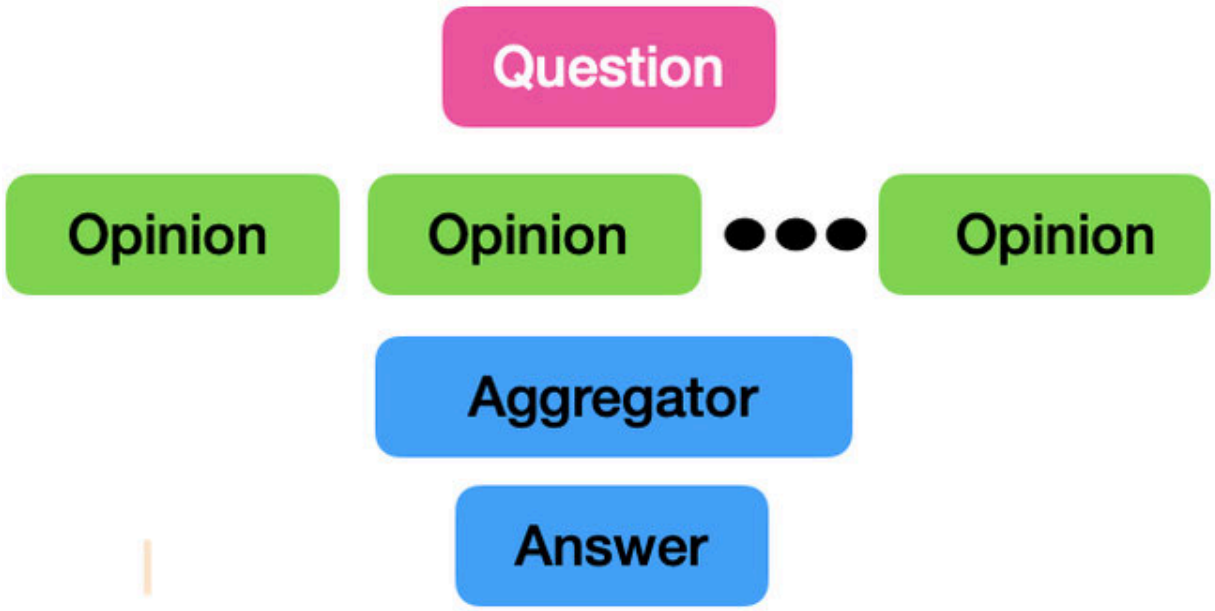
Edit | Submit entry

Bill Paseman

Introduction

Title

"Crowd Wisdom" Caregiver Agent



Short description

An Agent manages and aggregates a virtual “Tumor Board” of "Second Opinions" on rare disease questions using "Wisdom of Crowds" concepts

Your Submission

1. Abstract

Statistics

Most Medical conditions are not unusual, and can be treated in a hospital or doctor's office using the so-called "Standard of Care" (widely taught and widely accepted treatments). Success rate for such treatments is usually 30-80%. But for many conditions, there is no "Standard of Care". In this case, the patient may be directed to a Clinical Trial. The success rate for Oncologic Clinical trials is only 3.5%, making the patient's risk/reward calculation difficult. What's more, the "success" in such trials is often of short duration: usually measured in months, not years. And when Clinical Trials are exhausted, and in the case of rarer conditions which have no trials, the patient is in a tough situation, and any choice is likely to have less than a 3.5% success rate.

Tumor Boards

One typical solution to this problem is a "tumor board", where a team of oncologists, surgeons, radiologists, and other specialists, gather to discuss

challenging and complex cancer cases. However, tumor boards typically form within a single institution, whereas rare disease specialists are spread among multiple institutions.

Wisdom of Crowds

This dispersed expertise actually presents an opportunity to aggregate opinions that are decentralized, diverse and independent. An opportunity to tap into the "Wisdom of Crowds", which is the idea that larger groups of people can be smarter than just a few, better at solving problems, fostering innovation and coming to wise decisions.

We have used this "Wisdom of Crowds" approach to answer questions such as:

- Should I enroll in this clinical trial?
- Should I treat my brain meningioma with proton or photon radiation?
- What treatment do my tumor's "genes of interest" indicate?

This approach's workflow has been incorporated into a tool that allows the patient to

- Formulate a question
- Solicit opinions
- Judge and aggregate the opinions using several metrics
- Provide several answers based on the metrics and aggregation approach

The number of independent opinions is important. Two opinions are OK when the success rate is 80%. When it is below 3.5%, I have found that twelve or more opinions are better.

2. **Name/ Organization**
   rarekidneycancer.org

3. **Location**
   Saratoga, California, United States

4. **Navigation Area(s)/Task(s) Addressed**
   Monitoring for quality
   Connecting to available services

5. Problem Addressed

Rare disease Patients need to understand

- their situation
- their need for self-advocacy
- their need for a process to answer their questions.

The Situation

Most usual Medical conditions can be treated in a hospital or doctor's office using the so-called "Standard of Care" (widely taught and widely accepted treatments). Success rate for such treatments is usually 30-80%. But for many conditions, there is no "Standard of Care". In this case, the patient may be directed to a Clinical Trial. The success rate for Oncologic Clinical trials is only 3.5%, making the patient's risk/reward calculation difficult. What's more, the "success" of such trials is often of short duration: usually measured in months, not years. And when Clinical Trials are exhausted, and in the case of rarer conditions which have no trials, the patient is in a tough situation, and any choice is likely to have less than a 3.5% success rate. Unfortunately, even though the patient's situation is difficult, they still need to make decisions.

Self Advocacy

Patients are conditioned to trust their PCP (Primary Care Physician) to answer treatment questions. However, when asked about a clinical trial at a competing hospital, a physician recently said "If you want to know about their trial, talk to them." This is a valid response from a BMW salesman about a question on a Mercedes car, but not particularly helpful to a patient examining cancer treatment options, especially since once a patient participates in their first trial, they are no longer "treatment naive". I.e they can't switch "cars" (treatments) easily. Getting rare disease patients to understand that they, not their PCP, are responsible for their own care is difficult.

Process

Once the patient understands that they need to look beyond their PCP for answers, they need a process.

- **Questions:** What questions do I ask, and in what order?
- **Opinions:** How many people should I ask these questions and where do I find them?

- **Aggregation:** How do I weigh their answers?

6. Solution

One typical solution to this problem is a "tumor board", where a team of oncologists, surgeons, radiologists, and other specialists with appropriate expertise, gather to discuss challenging and complex cancer cases. However, tumor boards typically form within a single institution, whereas rare disease specialists are spread among multiple institutions.

This dispersed expertise actually presents an opportunity to aggregate opinions that are decentralized, diverse and independent. An opportunity to tap into the "Wisdom of Crowds".

"Wisdom of Crowds" is the idea that larger groups of people can be smarter than just a few, better at solving problems, fostering innovation and coming to wise decisions. However, where and how these opinions are solicited and acted upon (aggregated) is important. Key process characteristics include:

- Diversity - Each person should have private information.
- Independence - People's opinions are not determined by the opinions of those around them.
- Decentralization - Specialists draw on local knowledge.
- Aggregation - Ability to turn private judgements into a collective decision.

Example: EVEREST trial.

In 2014, I had my cancerous left kidney removed. Pathology determined that I had a rare (papillary) kidney cancer. I was offered an opportunity by my surgeon to participate in an adjuvant (preventative) clinical trial called EVEREST. So I consulted 13 clinicians and researchers.

- The first 3 said I ought participate
- 5 said I needed to make up my own mind
- 5 said I ought not participate

One "No" had run a clinical trial where Everolimus, the drug used in EVEREST, was used as first line (initial) therapy. The drug had not worked because

papillary is so different from "normal" kidney cancer. I chose not to participate.

Example: Proton vs. Photon

I let a meningioma grow for 9 years. I was then told I needed to treat it with radiation or surgery. I chose radiation. There were two types: Proton and Photon. Protons are nice because they don't exit the tumor. Photons are more prevalent. I asked 13 physicians. This was rather like talking to BMW and Mercedes dealers about the best car to buy. Each institution had already decided and recommended their equipment. However, one Institution in the Netherlands had both and recommended photon. Another clinician said "You're asking the wrong question. When you get a car repaired, you don't ask what wrench the mechanic uses, you ask how many cars they have successfully repaired". Using that advice, I was treated using photon at UCSF.

Example: Metastasis Treatment

Eventually, the kidney cancer may recur. And there are no treatments. So in 2018 and 2020, Pete Kane and I created a "Hackathon", where 80 researchers formed 17 teams examining my Blood/p1RCC tumor DNA in parallel for "Genes of Interest" and an associated treatment. Of the 17, one team scored very highly.

This process is automated. Humans and Large Language Models can opine on questions and aggregate opinions together or separately.

8. Video Demonstration

10. List of Data Sources Used

rarekidneycancer.org

clinicaltrials.gov

Apple Health

LLMs - Both paywalled (claude.io and chatGPT) and open access (Via Ollama) such as deepseek-r1:14b, llama3.2:3b, llama3.3:70b.

11. Technical Documentation

Crowd_Wisdom_Caregiver_Agent.pdf

11. Screenshot 1

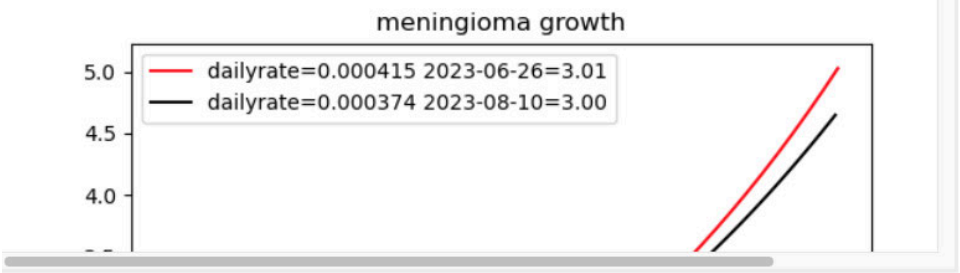
Patients | Clinical Trials | Questions | Agents | Opinions | Moderators

Select Patient

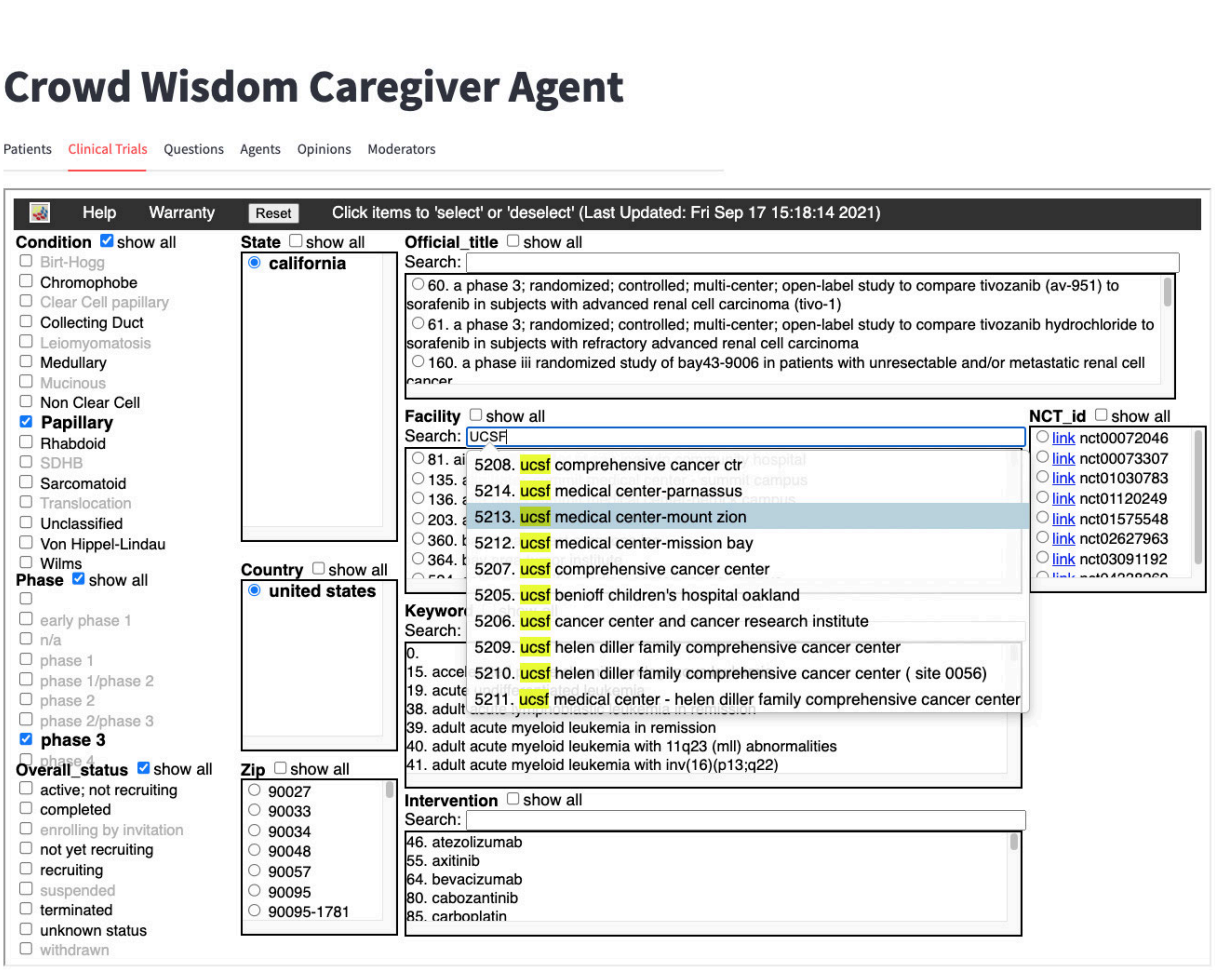
Bill Paseman

20220223 went for checkup for "Dysconjugate gaze" and "difficulty with tandem walking".
Head MRI indicated meningioma growth from 1 x 1.2 x 0.8 cm (20140220) to 1.8 x 1.6 x 1.5 cm (20220318). (differential image at bottom of this page)
Neurosurgery consults said Standard of Care is either Stereotactic radiosurgery (e.g. "Gamma Knife") immediately, or observation and surgery when the diameter reaches 3cm.
All Neurosurgeons concur with a Meningioma diagnosis.
All Neurosurgeons concur that the tumor does not explain "difficulty with tandem walking" and one suggested that I see a neurologist before proceeding.

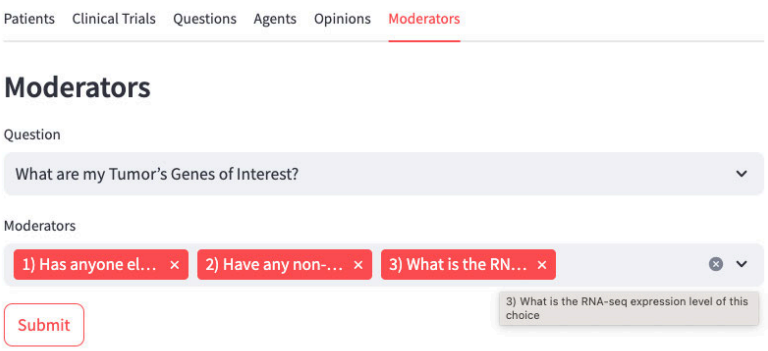
Date	Meningioma Dimensions	4/3*pi*LxWxH/8	Measured Volume	Findings
20140220	1 x 1.2 x 0.8 cm	0.5027	--	Final (page 7)
20151205	1.0 x 1.3 x 1.1 cm	0.7487	0.96 cc (20220525 UCSD 1:38)	Final
20220311	1.8 x 1.9 x 1.5 cm	2.68	Sutter	Final
20220318	1.8 x 1.6 x 1.5 cm	2.262	2.51 cc (20220525 UCSD 1:42)	Final
20220923	1.8 x 1.4 x 1.6 cm	2.11	2.66 cc (20221111 UCSD (20220525 was 2.48)	Final
20230911	1.8 x 1.5 x 1.6 cm	2.26	2.43 cc (20231025 UCSD)	Final



Screenshot 2



Screenshot 3



Opinions

	Moderator 1	Moderator 2	Moderator 3	Answer	ID	Argument
0	No	No	-0.668831	KNG1	Biomarkers.ai	x
1	Yes	Yes	-0.0465753	BARD1	GNOME	x
2	Yes	Yes	-0.0465753	BARD1	DeeperDrugs	x
3	Yes	No	0.02846798	SETD2	ExpressForce	x
4	Yes	No	0.02846798	SETD2	HSIEH	x
5	No	No	0.37044632	FHL1	Biomarkers.ai	x

Answers

	Moderator	Answer	IDs	Argument
0	1	BARD1	GNOME, DeeperDrugs	Overlap, including Experts
1	1	SETD2	ExpressForce, HSIEH	Overlap, including Experts
2	2	BARD1	GNOME, DeeperDrugs	Overlap, excluding Experts
3	3	KNG1	Biomarkers.ai	Minimum Expression
4	3	FHL1	Biomarkers.ai	Maximum Expression

12. User Personas

Bill

Bill (as of 2014), age 59, is a white male with p1RCC (a rare kidneycancer). No new research has been done on his disease for many years and the recommended treatment has a PFS of 9 months. That means after 9 months Bill has to try something new or let the cancer grow. Of the Clinical trials available, most target clear cell RCC, the most common kidney cancer variant. Fortunately, Bill has an opportunity to participate in a new clinical trial with minimal side effects. Unfortunately, once Bill participates, he is no longer "treatment naive", meaning that he is likely excluded from any future clinical trials. This is because the future physicians need someone with a "baseline" immune system to make their statistical results valid. And after Bill participates in -any- clinical trial, he is no longer treatment naive. Bill's primary hope is that he can survive until a new, better treatment materializes. Should he participate in the clinical trial?

Michele

Michele (as of 2025), age 58, is a black female with HLRCC (a rare kidney cancer). She was been on Avatar (avastin + tarceva) for 6 years. She recently had a liver intervention and so changed to cabozantinib mono in January then added Opdivo in February (2 cycles). The side effects have become problematic. High BP, low albumin (3 infusions), and her creatinine has spiked a couple times. She has chronic constipation along with Cabo digestive issues acid reflux, gas, vomiting and frequently needs to have ascites removed from her abdomen. Her Oncologist is watching the fluid closely and has consulted with the NIH. She needs a new medication. Michele's primary hope is that he can survive until a new, better treatment materializes. What medication should she take?

Katrinka

Katrinka (as of 2025), age 60, is a white Female with a heritable rare kidney cancer. She has one kidney in which tumors are forming. She needs a transplant but will not get one due to age and medical condition. What should she do?

13. Integration with Open Data

mCODE support was lacking. So I rolled my own interfaces using the resources below.

ClinicalTrials.gov

ClinicalTrials.gov is used to populate the clinical trial portion of the interface which links to particular clinical trial descriptions. Youtube provides videos on how to integrate with ClinicalTrials.gov.

Rarekidneycancer.org

I need to solicit opinions from rare kidney cancer specialists. Rarekidneycancer.org lists rare kidney cancer specialists from around the world. I originally identified them by attending GUASCO and meeting doctors personally. I then convinced one (Dr. James Hsieh) to co-found rarekidneycancer.org with me. We then met at the next GUASCO (2016) to formulate our goals and write a paper. Participation is spotty. However, besides publishing, another way to get participation is to get a referral and enter a particular doctor's system. This allows them to bill and they are then willing to answer questions. However, in the role of an advocate, when

I ask questions on behalf of another patient in need via email, I have a high response rate. After all, the overwhelming number of doctors I have come in contact with want to help people. All this communication is open. The email list is on rarekidneycancer.org.

Apple Health

I download my own health records using Apple Health (SMART on FHIR). It integrates and aggregates information from all of the systems where I have asked doctors questions.

- Mount Sinai Health System
- Loma Linda University Health and CareConnect Partners
- UCSF Health, UCSF Children's, Marin Health, and Affiliates
- Mass General Brigham
- CVS Health & MinuteClinic
- El Camino Hospital
- City of Hope
- Santa Clara Valley Health System

LLMs via ollama

Initial results was gathered with chatGPT and claude.ai. Both sites have APIs where prompts can be submitted and results collected. But its data is hardly open.

Now, I am using ollama and its (3 line) pythonAPI to query several "open" LLMs locally.

In addition to keeping the patient data private, the CareGiver app does not incur any monthly charges. This allows the Caregiver to sit quietly in a corner, protecting my data, downloading updates via Apple Health and (in the future) querying the literature for any new insights into my condition.

14. Public Health Impact

HIPAA

When I was initially diagnosed with a rare cancer in 2014, I figured I could research my own disease using public data stores. I then discovered that the data was ring fenced and siloed using HIPAA as the excuse for non-release.

Federated Data

To address this, I studied Federated data, and wrote a 2019 paper ("Mitigating Forgetting in Small Federated Learning Networks"). This approach allowed queries on data silos but with with minimal data exposure.

In 2021, I instigated a federated learning project at the Kidney Cancer Association with SAIL (an erstwhile competitor) to integrate data from various medical silos. After two years, we had nothing to show for it. Even with (minimal) funding, a list of participating institutions and a patent advocacy group, there wasn't enough momentum to crack that nut.

Government Funding -> Private Support

Congress has cut support for rare disease research this year. In particular, CDMRP, the kidney cancer research program I have lobbied for since 2020, has had its funding completely cut off this year.

So it is up to the patient to find their own solutions and do their own research. Fortunately, patients do have access to their own data. And many rare disease patients are more interested in treatments than data privacy(HIPAA). So in a world where funding is being cut and data is hard to get, perversely, rare disease data is a nice bargaining chip to recruit bioinformatics help. This is the argument Pete Kane and I used to get 80 participants into my Genomics Hackathon. Time, food and venue were all donated (i.e. no government funding).

The tool described here helps sort out clinical trial queries and research results for patients holding their own hackathons.

Federated Data Redux

And once there are enough patients who have control of their own data and put it in their own "Caregiver Agent", the tumor board will consist of three types of Agents: Doctors, LLMs and Caregiver Agents.

15. Deployment Plan/Considerations

For the last year, I have been developing the idea, and presenting partial results in a 6 trade shows to see what resonated. Here is a list milestones to date:

- 20240206 - EVEREST, ProPhoton, Hackathon Tumor Boards

- 20240910 - Large Language Models (LLMs) can submit Opinions and act as moderators
- 20250219 - Discovered "Wisdom of Crowds" book (2004) and reframed pitch , Noted Power Law distribution of Tumor Board Opinions. (This impacts the number of opinions required on the tumor board.) Introduced Caregiver Agents.

On the software development front:

- 20241231 - Decision Support Tool Mockup
- 20250416 - Single User App
- 2025xxxx - Caregiver Agent - As discussed in 20250219, The agent (will) run autonomously and encapsulate the patient's medical records and the tools described here .
- 2025xxxx - Caregiver Agents (will) themselves participate on Tumor Boards

As for the Patient Population

- Within all diseases, start with rare diseases
- Within rare diseases start with kidney cancer.
- Within kidney cancer, start with friends.
    - “If you work on frequent cancers, do randomized trials! If you work on rare cancers—find friends!” Olson, TA, Schneider, DT, Brecht, IB, et al.

16. Team Bios

Bill Paseman

After being diagnosed with a meningioma and p1RCC (a rare kidney cancer) in 2014, Bill co-founded rarekidneycancer.org with Dr. James Hsieh in 2016. In 2018 and 2020, with Pete Kane, Bill brought together 17 teams of more than 80 researchers who used Bill's medical data to determine “genes of interest” related to his disease. Bill then applied ensemble reasoning to evaluate the results of these hackathons (which Bill calls “gamified tumor boards”) to discover better ways to do cancer research. Bill is currently automating these “gamified tumor boards” using Large Language Models (LLMs) and is investigating how many "second opinions" are necessary in order to make good decisions for rare cancer care.

Bill is also involved in several patient advocacy organizations and is a CDMRP reviewer.

Prior to rarekidneycancer.org, Bill worked with Sabrina Paseman on mask braces (WO 2021/257123 A1), and using non-invasive Blood fluorescence to detect iron deficiency anemia (Patent 8,306,594). Bill also mentored Katherine Paseman who expanded Pulse oximetry technology to do non-invasive measurement of Hemoglobin and Hematocrit. Her work, "c <> 35H: A New Model Relating Hemoglobin, Hematocrit, and Optical Density" placed in the Intel Science Competition.

Bill, the 16th employee at Daisy Systems, left after the company had 1,000 employees to found Atherton Technology (which failed) and Calico Commerce (which IPOed), where he repurposed the music composition system he did as his Masters thesis at MIT to do interactive sales configuration over the internet (Patent 5,745,765). Elements of this are in the Clinical Trials Tab of the Caregiver application.

17. Additional Resources (link)

https://rarekidneycancer.org/blog

18. Contact Information

heroX@rarekidneycancer.org

19. Agreement to Terms

Yes

Edit

Submit entry

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