

Can group solve what baffles your doctor?

CrowdMed uses crowdsourcing to diagnose

BY TERRI YABLONSKY
STAT
Tribune Newspapers

Since its launch in April 2013, CrowdMed has claimed success in solving more than 700 of the world's most baffling medical cases, those that defy diagnosis despite multiple medical visits, expensive tests and sometimes years of suffering.

CrowdMed uses crowdsourcing, in which online "medical detectives" — retired doctors, nurses, medical students, researchers and former patients — pore over patient data and come up with the most likely diagnosis, often solving within days or weeks what may take solo doctors much longer.

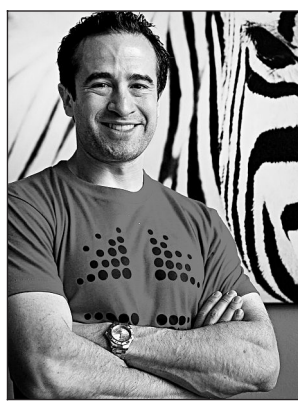
The average CrowdMed patient has been sick for eight years, has seen eight doctors and incurred more than \$60,000 in medical expenses, according to Jared Heyman, founder of San Francisco-based CrowdMed. The site's average case-resolution time is 60 days.

The concept is that the wisdom of the crowd trumps that of the lone expert.

Patients complete a questionnaire detailing their symptoms, medical history, test results, prior treatments and medications — all done anonymously. "We collect lots of data from them," Heyman said, "and we use that to generate their case."

Medical detectives evaluate the case, then contribute to a list of possible diagnoses. The CrowdMed community allocates points to possible diagnoses to express confidence in them.

CrowdMed charges



KARL MONDON/
BAY AREA NEWS GROUP

Jared Heyman founded CrowdMed after seeing the trouble his sister had trying to find a diagnosis.

patients a monthly subscription fee to post a case on its site. There are three packages: Lite (\$99), Standard (\$149) and Premium (\$249), with different levels of benefits such as the number of detectives on the case, presence of a case moderator and availability of expert case review. Some packages include compensation offers (called rewards) to attract the best case solvers. A \$50 deposit is required and refunded once a case closes, as long as the patient reports back to CrowdMed within 30 days. CrowdMed also offers an option for a free case submission for those with financial issues.

Heyman started the site after seeing his younger sister bounce from doctor to doctor with a debilitating medical condition nobody could diagnose. She spent three years searching for answers until doctors at the National Institutes of Health finally diagnosed her with a rare genetic disorder.

"Each doctor would do their best but only spend 10 to 15 minutes with her,"

Heyman said. "They'd give a narrow diagnosis within their specialty, but it was not a collaborative process. Doctors have a hard time seeing beyond their specialty."

Heyman had studied crowd wisdom at his previous Internet survey company, Infosurv. "I knew that crowds could be much wiser than the individual, but our medical system works in isolation."

He created an early prototype of CrowdMed and plugged in his sister's case. "We wanted to see retroactively if we could crowdsource the right answer," he said. With 100 medical detectives on the case, the CrowdMed community took just three days to correctly diagnose her.

CrowdMed has grown ever since. Case submissions have increased 60 percent per month the last several months on average, Heyman said. Seventy percent of patients report that CrowdMed's insights led them closer to a correct diagnosis or cure.

"We have a performance-based reputation system as opposed to a reputation-based credential system," Heyman said. "Anyone can sign up regardless of formal credentials, and over time as they prove they are as good as they are smart, they earn more and more status and influence in the CrowdMed community."

Since 2007, Beverly Perry, 51, of Lawton, Okla., saw close to 30 doctors to figure out the cause of her swelling, blood-pressure spikes, fever and flulike symptoms. Doctors thought she had cancer, so they removed her bowel and did exploratory surgery but found nothing. "They



JOHN LUND/BLEND IMAGES

also removed my appendix, right ovary, gallbladder and uterus, and nobody could find the problem."

She gave up and found CrowdMed in an online search. It took a few weeks, but someone suggested porphyria, a rare disorder of certain enzymes involved in blood production, she said. She took the diagnosis to her doctor, who had been testing her for unusual illnesses.

"Before I could even tell him what CrowdMed found out, he walked in and said, 'This is what you have.' And it was porphyria."

She's now undergoing treatment. "I spent hundreds of thousands of dollars over several years for doctors to diagnose what it took the CrowdMed community just weeks to figure out," she said. She provided a \$200 reward.

Arthur Caplan, head of the division of medical ethics at New York University Langone Medical Cen-

ter, said there is value in crowdsourcing. "You can certainly gather a lot of opinions and, to some extent, it's self-correcting if you have an extreme view."

But crowdsourcing has its challenges. "For one thing, those with time on their hands tend to participate," Caplan said. "You lose some of the best voices because they're too busy to do it."

Other caveats include lack of peer review as well as the belief that those who provide answers tend to be those with something to gain, Caplan said.

Crowdsourcing's usefulness may depend on the nature of the question.

Caplan said it works best when you're tapping people's expertise about their experience. "For example, cancer patients can share the best way to sleep while undergoing chemotherapy. But with just generic questions, you don't tend to get things of great value."

Crowdsourcing also

works well for gauging changing opinions, such as the best treatment or for identifying problems, such as in hospital safety, Caplan said. "I'm a little less convinced of its use with questions like, 'What do you think is the best care for your patient who has lung cancer?' Well, you haven't seen them. You don't know the particulars."

Online symptom checkers are common, but few resources exist for long-term chronic cases. One option is the Undiagnosed Diseases Program of the NIH. The program launched in 2008 and was expanded in July 2014 to include a network of health centers: Baylor College of Medicine, Duke University, Harvard Medical School, Stanford University, the University of California at Los Angeles and Vanderbilt Medical Center.

For information, call 866-444-8806 or visit www.genome.gov/27544402.



CULTURA

Social media sites allow parents to share the not-so-fun moments of rearing children.

Parenting truth often messy

Ortiz Healy, from Page 1

This is why, lately, I've become a fan of social media outlets and online offerings that celebrate the ugly side of parenting. The ones that give parents permission to bear the truth about things they hate, disgusting things they have to do and mean words family members actually say while trying to survive the challenging job of child rearing.

There's the #parenting-forreal hashtag that blogger Lauren Hartmann started in order to allow parents a place to share updates about the truth of parenting. A glimpse of the feed showed tweets about a deadbeat dad whose children no longer want to spend their weekends with him; photos from a mother complaining that her baby's closet is immaculately clean while her own looked like a picked-over rummage sale; and a Crock Pot recipe that consists of buying a bag of processed food and warming it up.

Another fun site is Scary Mommy, which features a confessional where parents admit to credit card debt, watching "Mad Men" instead of doing dishes, and taking anti-anxiety medication and smoking marijuana while exclusively breast-feeding.

And this month, Plum

Organics baby food company launched a campaign called #parentingunfiltered, which encourages parents to post pictures every Friday of moments such as when the baby gets into the dog food, a dad kisses a diaper and ends up with poop on his face or a mom locks herself in the bathroom for a stolen quiet moment to herself.

As of last week, the video ad for the campaign had been viewed 2.8 million times, prompting more than 12,000 comments, according to company officials.

"When we launched, we knew it would connect deeply, emotionally with people around the country," said Neil Grimmer, CEO and founder of Plum Organics. "We were a little surprised by how viral the video itself went and how much dialogue it actually created in the digital sphere."

I'm glad to hear that parents are finding these imperfect online communities in addition to the original ones that promote peer pressure and comparison.

Gabrielle Roberts, a child psychologist for Advocate Children's Hospital in Oak Lawn, warns that online sites such as Pinterest, Facebook and others have been known to promote something known

as the social comparison theory.

The theory, which dates to the 1950s, states that in the absence of objective data that allow us to evaluate ourselves, we compare ourselves with others. And recent studies show that doing so can lead to negative emotional consequences, Roberts said.

Interestingly, she added that too much exposure to the imperfect, complaining sites can also lead to similarly negative consequences.

"It's great to share experiences and to get support from other people. But you also have to take a step back and either feel OK about the choices you're making, or determine that you don't feel good about them and take an active stance and make a change, not just commiserate," Roberts said.

It's advice Shawn and I will take to heart as we power through these challenging, sleep-deprived days and on to new family adventures this summer.

Just don't assume we're succeeding if I post an image on Facebook or on one of the real-parenting Twitter sites. Because the truth will probably be somewhere in the middle and not on the Internet.

Dear Rahm: Please don't send CPS teachers packing



HEIDI STEVENS
Balancing Act

Dear Mayor Rahm Emanuel,

Please don't make Chicago Public Schools teacher an even less attractive career choice.

Please consider our city's more than 500 public schools the same way you consider its gleaming lakefront, enviable green spaces, world-class museums, storied sports stadiums and multiple corporate headquarters: a way to attract and retain a solid citizenry and compete with other cities in the global marketplace.

Please know that the quality of those schools begins and ends with the 22,000-plus teachers, the same teachers who are being asked to take a 7 percent pay cut next year, according to the Chicago Teachers Union.

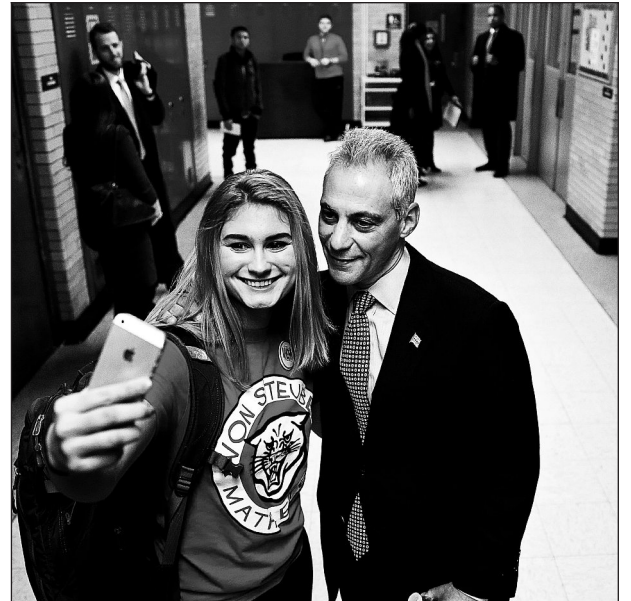
My two kids go to a CPS school. Every minute I spend with their classes — as a field trip chaperone, classroom reader, career day participant, awards assembly attendant — I am in awe of the weight of their teachers' responsibilities.

They shape and inspire dozens upon dozens of children every single day. They teach them the academic skills without which they could not function, let alone thrive.

They help them discover who they are, who they want to become and how to bridge that divide.

It's all I can do to not grab every teacher I encounter and beg, "Please don't stop doing this magic you're doing."

"Please look past the fact that you have a librarian but no library," I want



ANTHONY SOUFFLE/TRIBUNE NEWSPAPERS

Mayor Rahm Emanuel poses for a selfie with senior Ariana Lazia at Von Steuben Metropolitan Science Center. About 400,000 students attend Chicago's public schools.

to say. "Please don't think too hard about the fact that there's no school nurse, and the soap in the teacher's bathroom says 'Donated by (student's name)' and your class sizes have ballooned to 40 children, many of whom are economically disadvantaged and no doubt come to school hungry and tired and ill-prepared to face the day."

"Please," I want to plead, "don't flee for a tony suburb, where the schools come with large, paved parking lots, and the hallways are quiet, and the libraries are lined with beautiful new books, rather than students who've run out of classroom space."

"Please keep believing," I want to say.

I know a lot of CPS teachers, both as a mom and as a friend. They are dedicated to their students and their city. They love their jobs.

But I wonder when they'll say, "Enough." And I wonder what sort of future teachers — the education majors in colleges across this nation — would look at this mess

and say, "I'm in."

The best and brightest? The ones this city desperately needs to guide and educate its youth?

I hope, Mr. Mayor, that you help your fellow Chicagoans understand that the quality of our public schools affects every single resident.

Even if they don't have kids.

Even if, like you, they have kids but send them to private schools. The close to 400,000 kids in Chicago Public Schools today are tomorrow's doctors, nurses, architects, scientists, business owners, public servants and, yes, teachers.

We all need them to succeed, and no one makes that happen more than their teachers.

Please remember that in the days ahead, as the current teacher contract expires and negotiations get underway, and the rhetoric on both sides grows increasingly bitter.

Please give the teachers — and their students — something to believe in.

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