Episode 18: Forgotten No More Series: Marty Goddard, Inventor of the Rape Kit

Host: Leyla B Warsome MD

Guest: Dr. Jessica Anker

Guest: Pagan Kennedy

Published Date: 6/28/2021

Welcome to another edition of For Your Informatics, a podcast where we explore the limitless world of medical Informatics. Created and led by the Women in AMIA, we offer insights into career paths, leadership and education. Thanks for joining us as we highlight lives to inspire greatness inclusion and diversity in the field of Informatics.

**Dr. Leyla Warsome:** Hello and welcome to For Your Informatics, a podcast exploring the limitless world of medical Informatics. My name is Dr. Leyla Warsome, and I'll be your host for this exciting episode. Thank you so much for joining us today. We have the pleasure of introducing and interviewing our guest, Pagan Kennedy. She's a frequent contributor to The New York Times. She is the author of eleven books and has been a columnist for The New York Times Magazine, The Boston Globe and The Village Voice. She began her career as a chronicler of pop culture and underground design movement. We will be discussing Pagan's career and work on the innovation of the ricket system by the true creator Marty Goddard. Before we begin our conversation with Pagan, let's start with the background of the Forgotten No More series, which is developed by a team of five ladies from the Women in AMIA Leadership Program. The team is made up of Dr. Jessica Anker, Judith Dexheimer, Danielle Maori, Ud Young Artis Suchan Narayana. The series aims to highlight contributions from overlooked women in science and technology. Today I am honored to have Dr. Jessica Anker, professor, and vice chair of education of the Biomedical Informatics Department at Vanderbilt University in Tennessee. Thank you for joining me, Jessica.

**Dr. Jessica Anker:** Thanks so much.

**Dr. Leyla Warsome:** So tell me more about the Women in AMIA Leadership program.

**Dr. Jessica Anker:** The Women in AMIA Leadership Program was an amazing opportunity for a group of women to start developing the kind of leadership skills that we would need to take the next step in our careers and to develop to go into leadership positions in AMIA as well. The group was a pilot program that started in 2019, and we're hoping to continue it into the future in 2019. Dr. Wendy Chapman and other leaders at AMIA put together the idea, and they recruited women from universities and medical centers and Informatics companies across the country who were interested in leadership and brought them together for a series of meetings and activities with some didactic coursework, some interactive concepts and a series of in person meetings. Then the COVID epidemic hit, and of course, we switched to online only. But as part of that program, I think which we all really benefited from, we had to come up with a Capstone project, and our Capstone project was supposed to be something that would promote diversity in Informatics, and this is where the Forgotten No More Series came from. We had the idea of drawing attention to contributors to science and technology whose contributions might not be recognized today. Either their idea was not attributed to them or it became part of someone else's professional project. Instead, of their own. We found a number of these examples, and we were really interested in bringing attention to them by telling their stories because we want younger women to be able to see themselves in science and technology. We want them to recognize that we're not the first women in science and technology. In fact, there's a much longer history, but the history has been kind of forgotten. So the Forgotten No More series is meant to draw attention to and tell the stories of some of these forgotten pioneers.

**Dr. Leyla Warsome:** This is fascinating, but what does this all have to do with Informatics? Why is this a good fit for the FY Informatics podcast?

**Dr. Jessica Anker:** I agree it doesn't sound at first like it is Informatics, but the more that we thought about it, the more we realized this is Informatics. Biomedical and health. Informatics is all about the information. Where does the information come from? Who collects it? How is it stored and organized and managed? What Privacy and security protections are in place? How is it analyzed? And then how is it delivered to the people who need it to make decisions? And that's exactly what Marty Goddard's innovation was that she recognized that we needed a standardized approach to collecting rape evidence and making sure that evidence and that data got to the decision makers so that there was some chance that these cases would be prosecuted and could be prosecuted successfully. So she recognized that part of that gap was all about the data. And that's why I think this is really relevant to modern biomedical Informatics. Even though no computers were involved, it was all paper based checklists and envelopes. But you can see the connections to what we do with a lot of biomedical and health data today.

**Dr. Leyla Warsome:** So do you have any information to pass on to our listeners on how to get involved with the Forgotten No More series or even the Women in AMIA Leadership program?

**Dr. Jessica Anker:** That's great. We'd love to hear from listeners. So I guess the first thing is, if any listeners have nominations for a Forgotten pioneer in science and technology that they'd like to see profiled in the Forgotten No More series. Please let us know there's a feedback form in the podcast page, and we'd love to hear your nominations so that we could add them to the series. For people who might be interested in the Women and AMIA Leadership series. We are trying to move that forward and start recruiting for future cohorts so that more people can take advantage of this terrific opportunity. So we're currently in the fundraising phase and the organizational phase, and we will be making public announcements soon about when the next leadership sessions will be offered and how people can either self-nominate or nominate other people to join this project.

**Dr. Jessica Anker:** Thank you so much for joining us, Jessica. I really appreciate all the information, and this is excellent work. Thank you so much. We're really glad that it's getting these forgotten stories out there so more people can learn about them and be inspired by them.

**Dr. Leyla Warsome:** Thank you so much for joining us, Pagan.

**Pagan Kennedy:** Thanks. Thanks for that. Great introduction.

**Dr. Leyla Warsome:** If my introduction is sufficient or if you want to add some elements that I might have forgotten, would you mind introducing yourself to our listeners?

**Pagan Kennedy**: So I just wanted to add that I began switching into reporting on science and technology about 15 years ago because I really wanted to bring a political and cultural spin to science and tech writing and was really thinking a lot about how science and tech really are becoming pop culture and political culture. So that was what brought me into this. I was trying to bridge that gap. And then I did a yearlong fellowship at MIT, where I had an opportunity to learn a lot about data and statistics and all the things you guys study.

**Dr. Leyla Warsome:** It's amazing. I never knew that journalism could actually get an MIT fellowship on science and technology. It makes me think that I should pay more attention when I'm reading those kind of columnist in The Times, can you tell us how you got started on this story and what piqued your interest in the rape kit?

**Pagan Kennedy:** So for about a couple of years, I was doing a column for the New York Times magazine called Who Made that, and they would give me an object. And then I would tell the story of how it came into the world and who made it. I had always really been interested in origin stories. And so that was a kind of graduate school education and invention, how it happens, who does it and how to track them down when they've disappeared. And I went on to write a book called Inventology, in, which I talked a lot about how invention happens, who does it and who should do it. And then I was kind of working on a follow up book about I got really interested in what technology would look like or does look like when it's invented by and for women, because so often technology is under the control of men. And so even when it is originated by women, their vision may not make it through the system. And so I was just really interested in that. And so I was working on that book, which is no more because one of the objects I was interested in was the rape kit. And that story just turned out to be so incredible that honestly, I wasn't planning or I never made a decision along the way. It was just like I fell down that rabbit hole. And so I would say the first stumble into the rabbit hole was when I actually began looking into what other people had written about the history of this sexual assault forensic system with this kit that most people have heard of but may not know too much about. And I read on Wikipedia and elsewhere that this was the invention of a crime lab, a police officer named Lou Vitullo in the 70s, with some help from an activist named Martha Goddard. And so I was very interested in what actually went on and what their collaboration was like and what happened and how it happened and what was the story there. But one thing that was really weird. Louva Vitullo was dead and there were Obits. But I could not find anything about what had happened to Marty Goddard, and I couldn't find a death certificate. I called up the apartment building that was her last address, all the numbers, nothing. I couldn't find her. But I did find some of the activists and some of these amazing women who had worked with her in the early 70s to reform the policing and forensic system. And one of them was named Cynthia Gary. And I was on the phone with her one day, and she just sort of burst out. She's like, Pagan. I have to tell you that it did not happen. The way you've read about that, this was all Marty's idea. She had the full system in mind. She had the design, and she went in to see Lou Vitullo, who was then head of the Chicago crime lab. And he threw her out. He yelled at her. She called me. Cynthia said she called me right after that meeting where she was thrown out of his office, and he told her she was an idiot. But gradually she managed to convince him that this whole thing was his idea. And he took ownership of the idea. And part of the way she got the system into policing was to name the kit after him. It was originally known as the Vitullo kit, but she did all the training as far as I am able to tell a large part of the design. Of course, he did contribute. She raised all the money. Interestingly, from the first grants came from the Playboy Foundation, which is another story in itself. And she just really kind of took on the whole thing herself and then moved to other cities like New York and began training medical staff and police in this almost like a new forensic language that would bridge the gap between the nurses who examined sexual assault victims and the police departments and detectives who were investigating. And they didn't really have a common language before this kit.

**Dr. Leyla Warsome:** So what led Martha down this path?

**Pagan Kennedy**: So she began investigating. She just talked to a lot of people almost like a reporter would. And she'd find that the first of all, you need to understand that in the 70s, the attitude about sexual assault was so different from today that police not that it's great today, but it was a lot worse. Police would generally treated assault as something that could never be proved, that it was always going to be, he said, she said, you just didn't prove it. They didn't even make an effort, really to collect evidence. When a woman did come in or a victim did come in to the hospital, the nurses might believe her, and they would do their best to collect evidence. But nobody had ever trained them in forensic evidence collection. So the problem was they wouldn't know how to do it. There was no system in place, no sort of standardized method. What she did was create this method. And it was partially a way to keep the crime lab workers from throwing out all the evidence and just saying, well, the nurses, they did a terrible job. It's all their fault. They didn't collect the evidence. So she created a system where everybody had the same expectations and knowledge about what was data. How would it be collected, how it would be filed away, and how it would be shared? And so she was really thinking about creating this data system. And this was really remarkable because it was before the existence of DNA forensics. So of course, all of that became a lot more useful in the 80s and 90s as DNA fingerprinting and analysis was available. And these swabs of DNA suddenly were a lot more useful to investigators.

**Dr. Leyla Warsome:** So what is the current process of the Rape kit system? And who does the administration, the collection follow up?

**Pagan Kennedy**: So there is not really one system which is part of the problem. Each state has its own sexual assault kit, and they're not user friendly. They're very analog. Still, they haven't changed much from the 70s. The New York state one has, like, a four page, incredibly dense instructions. In theory, the nurse who's doing the exam is trained. But in practice, most nurses probably have not done it before. Many nurses. So the nurse is trying to understand this, and it's now gotten more and more stuffed with envelopes and doodads. So it's incredibly complex. And often the nurse is there with a very traumatized person trying to do this exam and not understanding and trying to read the directions. And it's just incredibly unwieldy. And there's no yet very few States have adopted any kind of digital tools, like, for instance, a phone app that would lead the nurse and the victim through the exam with really clear instructions and visuals that would be super easy, like a YouTube video or something like everybody learns cooking from YouTube. But we don't have that. There's nothing like that in the system. It just really has not changed. But then another problem is that it's very poorly funded. So a lot of hospitals don't have this available. So if somebody is assaulted, they might have to drive for 6 hours to go from hospital to hospital. And it's incredibly burdensome on the victims themselves. They may have to wait 12 hours in the emergency room just to get seen, and then maybe another 5 hours of the actual exam. And this is all in the wake of the worst day of their lives still wearing that they can't shower. So this is the reason why very few victims decide to go forward because it's incredibly burdensome on them in this system. And then the data itself is owned and managed by police departments. And I think most of the listeners will have heard of the rape kit backlog, and the way that police departments have either just stockpiled and failed to test kits or openly trash them and throwing them away so that police ownership is very problematic. There's a real lack of transparency.

**Dr. Leyla Warsome:** And given that in the past year, we have experienced major shifts in medicine and the justice system, how do you feel the pandemic has affected this process of the rate kit system?

**Pagan Kennedy:** I just think so much has changed underneath our ground during the pandemic, and we're only just realizing it. So it's not just the obvious problem that when the hospitals were full of people with COVID, there was no way for victims to go in and file kits. There were no nurses available, it wasn't safe. So the system completely broke down in the pandemic. And so I did find one nurse I talked to had created her own workaround in one California location where she had created almost like a home delivery contactless delivery system for the kit, where the police officer would bring a kit, and then the victim would use telemedicine to examine herself and collect the data with forensic nurse monitoring it and witnessing it. And that was something that I heard because I was reporting on this pre pandemic. I heard people discussing that as a kind of utopian crazy idea to create a system that was much better for the survivor herself or himself. But it's something that could never, ever happen because there was too much inertia. But it's amazing how having the entire hospital system breakdown will tend to change things. But there's now real discussion happening about how much police should own the data, whether they should own the data, and really, what kind of system would we put in place if this were designed around the needs of the survivors rather than the needs of the criminal justice system and the ease of policing and what prosecutors want to build a case as opposed to what the victim actually needs after an assault. So there's a lot of discussion. This is part of the whole discussion. There's a larger discussion about defunding the police and rethinking what kind of measures we take for public safety and who comes to your door when something terrible has happened? And that's just a really big. We haven't yet really had the discussion about sexual assault. And how much should a police officer with a gun show up at your door if you've been assaulted? What is the ideal method? Should there be? There's just all kinds of people with all kinds of ideas about how this could operate. And there's a lot of interesting experiments going on right now. So it's really just like policing in general. It's kind of this crazy, wide open moment where people are really rethinking the idea of justice, public safety, what could be possible. And we've had that around policing in general and these police stops and police violence. But we haven't really had that discussion around sexual assault and policing. And I think we really need to and especially the issue of who owns the data.

**Dr. Leyla Warsome:** Absolutely. Now, you mentioned earlier that there's just been some minor changes to the rate kit since its creation in the 1970s are there some considerations, in your opinion, that would improve the collection of data using technology?

**Pagan Kennedy:** Yeah. First, there's this wonderful designer named Auntie Wagman who did at the same time, I was falling down the rabbit hole as a journalist. She was sort of falling down it as a designer and did such amazing research, talking to lots and lots of people about what they want if they were assaulted. She was inside the hospitals working with victims. She was seeing what actually happens during a sexual assault exam and the ways that the kit was too complicated, not helping. She really thinks that there should be an app that guides the data collection so that it's easy for everybody. But why wouldn't we use that kind of tool? But at the same time, what comes up in my mind is how much of evidence these days is digital. Of course, DNA swabs are really important, but in many cases, there may not be a DNA swab. There may be a text chain of somebody threatening the victim or even coming out and saying the perpetrator, saying what he's going to do or making these threats, or there may be photographic evidence on a phone. And I'm sort of surprised. It seems like from my research that is not really collected. It's not made part of the kit. I just think that there's a real opportunity for your listeners to go out there and work on this. Come up with better ideas. Actually, I talked to a number of female scientists who are thinking about the actual way that DNA is processed and changing that from the ground up for sexual assault, because there's different ways of processing it where you could first sort out male and female DNA. And since so often it's a male attacker and a female victim that could radically reduce the cost of processing the DNA. Things like that where if you just start looking at, honestly, the system is so broken that you can pick any piece of it and just start looking and finding, like, obvious fixes. It's just even hard to know where to begin.

**Dr. Leyla Warsome:** Absolutely. So there you have it, folks. Pagan laying down the challenge to all the Informatics folks out there how to best make this system work. Thank you so much for your time, Pagan, and for sharing your work with us in the world. I wish we had more time and I would love to know so much more. So I'll be definitely looking out for your book that's coming up. And it's been wonderful to hear about Marty and how she created a unified data system that included DNA and blood sampling at a time when DNA science was in its infancy. How she noted that there was a lack of standardization of the rape kit and how it varies from state to state, and how she tried to be on a crusade of her own, funded it and went from state to state, trying to teach people how to do it the correct way. And finally, an age old question about data ownership and governance, and should data belong to the justice system, the medical system, or the survivors of this crime? So any last words of wisdom for those listening whose innovations may have been forgotten or overlooked?

**Pagan Kennedy:** Well, I've been writing about inventors for a long time and talked to so many inventors, and so I would say that a number of them are people who noticed a problem that nobody else saw. And it was usually a problem where that they themselves suffered from. So I would challenge everybody to think about what are the problems that are bothering them now and may seem unsolvable. But if you can put that problem into language and actually identify it and name it and begin to break it down, you are on the path towards coming up with an incredibly new idea for solving it. I mean, half the battle is sort of identifying and naming the problem, and that's often where it begins with these really big new ideas.

**Dr. Leyla Warsome:** Thank you again so much for joining us today. This is Dr. Leyla Summit with Pagan Kennedy concluding the For You Informatics episode in the Forgotten No More series. Thank you again for listening.

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