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**Army of Women and caBIG<sup>®</sup>:**  
**Uniting Women and Researchers Through Biomedical Informatics**  
*caBIG<sup>®</sup> Podcast Network*

**Moderator:**

Welcome to the caBIG<sup>®</sup> podcast network. In this podcast, we will highlight an exciting new collaboration between the Dr. Susan Love Research Foundation and caBIG<sup>®</sup>. This collaboration is designed to leverage biomedical informatics to connect women and the research community in a common effort to combat breast cancer.

Today we have with us Dr. Ken Buetow, a geneticist and head of the National Cancer Institute's bioinformatics program and visionary for its caBIG<sup>®</sup> effort. Also joining us is Dr. Susan Love, a world-renowned breast cancer expert and advocate, as well as president of the Dr. Susan Love Research Foundation. Welcome to both of you and thank you for joining us today.

**Dr. Love:**

Thank you.

**Dr. Buetow:**

Thank you very much

**Moderator:**

By way of background, Dr. Love, let's start by having you tell us a bit about the Dr. Susan Love Research Foundation and how you joined with the Avon Foundation to form the Army of Women

**Dr. Love:**

The Dr. Susan Love Research Foundation is an independent, non-profit foundation doing research on women to try to find the cause and how to prevent breast cancer, and in our research projects we found that there were a lot of scientists who were doing their research on rats and on Petri dishes and said, 'oh, I wish I could do it on women, I just don't know how to find them.' And I said, 'you know, I can find them.'

So, we started the idea that we could recruit women from around the country who were willing to participate in research, and help these scientists move the field forward, and we presented this to the Avon Foundation and received a grant from them to start the Love/Avon Army of Women.



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### **Moderator:**

I'm wondering if you can tell us what led you to NCI and caBIG<sup>®</sup> for this project.

### **Dr. Love:**

We started the Army of Women in October of 2008, launching it on multi-media platforms and we have a scientific advisory board that helps us in terms of figuring out which studies we should send to our women to help connect them with them, when I said 'I'd love to figure out a way where the researchers who use the Army of Women could share their research and make it available to everyone,' and my scientific advisory board said, 'you should talk to caBIG<sup>®</sup>' – and so, I gave them a call and we immediately started off how to make things bigger and better.

### **Moderator:**

Dr. Love, can you describe the Army of Women/caBIG<sup>®</sup> collaboration in further detail?

### **Dr. Love:**

One of the problems we've had with the Army of Women is that we don't have enough projects for all the women who have signed up. We have over 300,000 women. So, in talking to Ken Buetow, we came up with the idea that this was the perfect resource to launch the first cohort that was totally done online.

So what the collaboration is, is to recruit from the Army of Women the women who are willing to be part of a longitudinal cohort, and all of it will be done online. Women will sign up, they'll receive their questions online and fill them out, and we'll have immediate access to the cross-sectional data, and we will also be following them longitudinally over time to help us pick out what the causes of breast cancer are.

Our goal is to have a million women and because we're doing it online, we should be able to be fairly nimble about what we can do and what questions we can ask.

### **Moderator:**

Dr. Buetow, what do you hope to accomplish with the Army of Women/caBIG<sup>®</sup> collaboration?

### **Dr. Buetow:**

Well what we hope to accomplish through this really exciting, revolutionary partnership, is the demonstration of a new, 21<sup>st</sup> Century model of research, one that is empowering of consumers and one that is technology-enabled. caBIG<sup>®</sup> in this partnership will be providing the biomedical informatics support, developing easy access web-based software that connects the women and researchers with the goal of improving prevention, diagnosis and treatment of breast cancer.



More specifically, what we're going to attempt to do is utilize web technology and connectivity and collaboration to facilitate the women signing up and responding to secure, online questionnaires concerning their family health history, and then facilitating authorized researchers to access this information in partnership with the broader collaboration of the Army.

### **Dr. Love:**

You know, doing it this way with caBIG<sup>®</sup> has really enabled us to do things differently than they've been done before. We can sort out different cohorts, we'll have a sub-cohort of survivors we're following, we'll have a sub-cohort of healthy women, and we can do that on the back end without having to recruit from the beginning, as far as the women are concerned, they're all in the same study.

### **Dr. Buetow:**

I think that what's most important to think about this is, is that we really are transforming the entire cancer research paradigm. In this transformation, just as what Susan's indicated, we don't have to pre-contemplate everything that needs to be done, and put in place elaborate infrastructures, in advance of asking questions of importance - but more importantly, the infrastructure allows us to be immensely dynamic.

As new and interesting questions emerge, we can in real time ask those questions, and in real time, conduct studies that leverage, very cost efficiently, information technology resources that provide us to get almost immediate answers to those questions.

### **Moderator:**

Dr. Buetow, has such an online community been tried before?

### **Dr. Buetow:**

To the best of our knowledge, this new framework for conducting biomedical research is absolutely novel. This is the first 21<sup>st</sup> Century biomedical research network that puts consumers centrally in control of what's going on, as well as then leverages next generation information technology to support the collection of information and the aggregation of information that comes from the downstream studies that will be conducted utilizing this very important cohort of women.

### **Moderator:**

Dr. Love, how do you think this effort will improve prevention and care for women?



### **Dr. Love:**

A lot of the research in breast cancer, has focused on treatment, and we have made some progress in that regard, but we really have not made the same progress in looking at the risks of breast cancer and how to prevent it. And that kind of research can't be done unless you have a very large study, because once you start having subgroups, your power disappears pretty quickly to figure anything out. So I'm hoping by having a million women, some of whom will get breast cancer over the course of the next 20 years, we'll be able to start to parse out these different risk factors.

### **Moderator:**

Dr. Buetow, what do you think this collaboration will do for cancer research?

### **Dr. Buetow:**

Well I think it's fundamentally transformative. First, it's unprecedented in size. Second, because we're using information technology as a connector and an enabler, we're going to be able to join disparate types of information and intersect a whole collection of different types of studies that will be conducted against a common collection of women.

Moreover, because it's electronically based, the rate-limiting step for conducting studies won't be how rapidly can we construct a survey or, how quickly can we get to creating some particular resource, there's a true democratization that occurs out of this, the women themselves are now empowered to provide this critical information to a broad collection of investigators across the entire cancer gamut.

### **Moderator:**

Dr. Buetow, can this same process be initiated for other diseases, beyond breast cancer?

### **Dr. Buetow:**

Unequivocally. What's exciting about this is, this specific platform and this specific collaboration has the capacity to look at other forms of cancer besides breast cancer. More pragmatically and more mechanically, the physical platform that's been created here could be used to study other diseases, or be applied in other disease communities.

### **Dr. Love:**

I totally agree, we're starting the cohort focused on breast cancer because of course, that's been my area of primary interest – but when we have a million women giving us their information and answering questions every month, it would be a crime not to use it to look at other diseases that afflict women and then, we can get the women to bring their significant others in, and before you know it we'll have a bigger cohort of even men and women. I think this is a great way to engage the public in the greater promise of research, and in the greater research program.



### **Dr. Buetow:**

And to further echo that, I would add that this breaks down the sort of invisible wall that traditionally exists between the research community and the participants in research. Moreover, it truly makes the consumers, the people who are the beneficiaries of research, the owners of the research activities.

### **Moderator:**

How can other scientists and researchers get involved in this collaboration?

### **Dr. Love:**

We're very eager to have other scientists and researchers be involved in this process, and if there are epidemiological type scientists and they have questions that they would love to ask a cohort or a sub-cohort, they could just approach us. In addition, if they have new ideas for how we can use this or make this work, we're very open to that, and basic scientists who need specimens or need information about any women can recruit through the Army of Women.

### **Dr. Buetow:**

One of the things we're very much excited about seeing is opening this to scientists who may be able to take the existing platform of information and ask new questions against that platform. So, key to this is to have as many scientists eyes look at this data that was both primarily generated first by the cohort, but also the contributions of novel data that were generated by the scientists, so that the whole can become much more than the sum of the parts.

### **Moderator:**

Dr. Buetow, what does this collaboration mean for caBIG<sup>®</sup>, as a major initiative of the National Cancer Institute, as well as for the larger biomedical informatics community?

### **Dr. Buetow:**

Well I think it's an incredible proof of concept that this new model can and will work. It's in many ways a culmination of what we've been investing in caBIG<sup>®</sup> over many, many years. The project itself leverages infrastructure that we initially created for caBIG<sup>®</sup> to support another activity, so it shows the power of the use and reuse of open source software – but more importantly, it provides a critical demonstration that this information-based medicine and information-based research is the exciting new paradigm by which we can begin to ask and answer questions that simply were unapproachable when we were capturing data and locking it away in individual laboratories, or, when the only source of information was what you could read from individual journals.



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**Moderator:**

Dr. Love, could you also discuss what this collaboration means for the Dr. Susan Love Research Foundation?

**Dr. Love:**

We would not be able to do this project without the collaboration of caBIG<sup>®</sup> and leveraging a lot of what has been done already and has been built by caBIG<sup>®</sup> and BIG health, has allowed us to jump start. So, from the first time we started talking about this around the beginning of the year, it will be about nine months before we have this, in fact, launched and the beginning of the cohort. To be able to work that quickly could only happen in a collaboration like this—it just can't happen if we did it all by ourselves.

**Moderator:**

Thank you both so much for joining us today and for telling us more about this exciting collaboration. This concludes our podcast on the Army of Women and caBIG<sup>®</sup>, uniting women and researchers through biomedical informatics. For more information on caBIG<sup>®</sup>, please visit [cabig.cancer.gov](http://cabig.cancer.gov). To learn more about the Army of Women, visit [www.armyofwomen.org](http://www.armyofwomen.org).