Catalyzing Computing Episode 34 - Health Informatics with Katie Siek (Part 2)

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[Intro - 0:00]

Khari: Hello, I'm your host, Khari Douglas, and welcome to Catalyzing Computing, the official podcast of the Computing Community Consortium. The Computing Community Consortium, or CCC for short, is a programmatic committee of the Computing Research Association. The mission of the CCC is to catalyze the computing research community and enable the pursuit of innovative, high-impact research.

In this episode, I interview Dr. Katie Siek, a CCC Council Member and a professor in Informatics and the Chair of Informatics at Indiana University – Bloomington. Dr. Siek is interested in integrating pervasive technologies in health and wellness environments to study how technology affects interventions. Her research interests include human computer interaction, ubiquitous computing, and health informatics.

This is part two of my interview with Dr. Siek. If you haven't heard part one and would like to, go catch that and come right back. In this episode, Katie discusses health disparities and how computing technologies can play a role in the

reduction, as well as the challenges to doing health informatics research in the field. Enjoy.

[Sociotechnical Interventions for Health Disparity Reduction - 1:07]

Khari: So a couple of years ago, you were one of the organizers of a workshop the CCC did on [sociotechnical interventions for health disparity reduction](). Can you give an overview of what that workshop was about? What are health disparities and why do they need to be addressed?

Katie: Yes, sure. So health disparities are when we see differences in a group's health outcome. It's anything from disease diagnosis to survival rates, when we compare that with the general population. So groups that experience health disparities range from [being based on] socioeconomic status, race, gender, disability, sexual orientation, and where you live — for example, rural versus suburban or urban. Besides just being the right thing to do, by addressing health disparities we want to improve equity and the overall health of the population. But, if appealing to humanity isn't enough, then you can think of it financially — everyone pays the cost when we have groups who are suffering health-wise. That's why we have to address health disparities.

Researchers have been saying for years that technology can improve health disparities, my work included. Like, we can't afford a dietitian for everyone who needs it. Great, let's give them an app to do it on. There's no specialists in your community. Fine, let them visit the online clinic. But research studies have been kind of small. Most of the time they're prototypes systems, so we have to make sure the small before we go broadly.

Also, this work has been done in silos. There's researchers in computing working on health disparities, like myself. There's people in health and medical informatics, there's people in behavioral medicine. There's also researchers who actually do research just in health disparities. In this workshop we wanted to bring these four groups of researchers together, share what we know, learn about what we don't know, and identify gaps.

Khari: So what are the biggest challenges or limitations, currently, to using technology to address health disparities?

Katie: There are so many. Just a few are access to technology and the Internet. We see that here, largely for the Internet. It's just amazing. My co-organizer [Tiffany Veinot]() and some colleagues just wrote a paper about how the Internet is kind of like one of those requirements for life now. We just need it to survive. And the truth is, in rural settings, in the research I do in southern Indiana, we'll talk to Comcast or the local Internet provider

and they're like, "If you're not within 500 meters of this road, you don't get Internet." So what can we do? We have to spend a whole lot of money on satellite and wireless if it's available in the area.

There's also issues with technology in terms of usability and understandability. If people don't have technology, if they don't have access to the Internet, their understanding of how to interact with these apps is not universal. Then we have cultural norms, especially within groups who experience health disparities. There's various cultural norms that are going on that we must address to make it personalized and relevant to them. Finally, it's the understanding of the context, kind of like that story about doing a workshop and teaching about cooking. Understanding the context there...I was kind of like, "Oh, yeah, I cook for my family. I cook for one day a week, and then we eat the leftovers during the week. I'll show them how to do it." And then working in their kitchen, working with the resources they had, all of a sudden it was like, this is different and we have to kind of adapt.

That's just one context, but kind of understanding how this all impacts their technology use and their health. One of the standard examples, but it still stands in my mind was, just that one of the health disparity researchers was talking about an intervention where an app would remind you to go for a walk. But then the person would say, "I don't feel comfortable walking in my neighborhood."

If you or I are designing this app we would be like, "Sure. Go for a walk. Sounds like a good idea." Whereas to understand, what's the walkability of the area? What's the safety of the area? What is the weather like? You mentioned you're in Seattle — what's the weather like? Do you want to go for a walk right now? So all of this is important when we're addressing technology for everybody, especially those who experience health disparities.

Khari: Ok. So one of the things [the [workshop] report](#) talks about are structural versus intermediate determinants of health. What are those two things and how can they be affected to improve or reduce health disparities?

Katie: Yeah. Structural deterrents, these are the causes of health inequalities — namely power and resources. A typical instance here are government policies that may impact one's job or housing or education access unequally. That's kind of a structural determinant.

Intermediate determinants of health are underlying causes of those structural determinants. For example, do you have the financial means to go to that doctor? Do

you have the social support to seek assistance? Will you change your behavior based on what the doctor says? These are the intermediate determinants.

So, how do these work to improve health disparities? Well, one [thing] is we need to know the answer to those questions.

[Laughter]

The other is what kind of information can we provide to you to make it actionable so that you can get it? One of the hard things about health disparities istat a lot of times it's not technology, right? It's not technology and it is all at the same time. We can collect data to present it to policy and decision makers to say that we need a policy, we need resources to help, and then we can start bringing in technology interventions.

Khari: One thing that the report mentions is upstream versus downstream interventions. What's the difference between those two things?

Katie: Right. So in upstream, what you're kind of thinking about here is how we can improve health for larger groups of people, typically through policy provisions. From a technology point of view, this is where we're gathering information, gathering data, and using that data so that we can impact policy.

Downstream interventions typically focus on the health of smaller groups and providing them equitable access to health care. In computing we typically focus on those downstream interventions, mostly because we know how to do technology well for small groups and also it's what's accessible to you. A lot of our research is localized, based on where we are, especially with the way our grants work. I can't go all over the place. We also have to make sure that we can actually see some improvements in those prototypes for those smaller groups.

We're slowly moving upstream. You can kind of see through time as we're moving upstream, but this takes a lot of time, resources, collaboration, and knowledge to kind of bring us up so that we can impact the policy level.

Khari: Ok, another aspect of the report is sociotechnical black boxes. I know black boxes are talked about in AI and data science pretty often, but what is a sociotechnical black box?

Kate: Right. So, when we're designing technology for certain groups, sometimes it works, but we're not exactly sure why it works. Is it the design of the interface, is it the

technology? A lot of times, too, we use these social behavioral theories. But the mapping between the theory and the tech is not always one to one. For example, a lot of social behavioral theories will talk about reflexion. Have people reflected? Especially for diet. Have you reflected on your diet and how do you do that in an app?

Well, one way I've done this in my own research is I'm like, "Ok, I'll create a page that shows everything that you've eaten in the last day or week. And then I will track user behavior. If you click on that page and you spend more than five seconds, I'll say that you looked and reflected on what you ate." But is that truly that mapping? It's a little bit of a sociotechnical blackbox in that we're doing these mappings between theory and digital technology, and we are not quite sure what is actually working to change people's behavior. We want more work done to think about that.

The other great thing we learned about at the workshop with regards to social behavioral theories, and that the behavioral medicine researchers pointed out, is that a lot of theories were created at a time when we had...They were created in college campuses with students, and during that time a lot of the students were white males. So if we're trying to apply a sociotechnical theory to an underrepresented group who are experiencing health disparities, is it the theory to use? So we also need some theory work there.

Khari: Yeah, that makes sense. So are there any other key takeaways from the report that you want to mention?

Katie: Yes, definitely. One of the things is that we really need to do more research with groups that experience health disparities. Like I mentioned earlier in this interview, we need resources to, kind of, help both groups. It can't just be researchers with funding for researchers to come in. We need to ensure that everyone is supported in this research. And we have to have social behavioral theories that can work with various diverse populations, since, as we talked about, most of them were created before campuses were more diverse. And we have to design systems that could be used on a large scale to support those upstream interventions. So we are creating prototypes. We're seeing if they work. That's great. We need that bridge funding to go from a small prototype to a larger deployment.

We also need to make sure everyone at the table has a voice. This is really important, I think with all design, but especially with those who experience health disparities because we want them to be able to participate in the research and give us feedback on what's going on. How do you empower everyone to feel that they do have a voice at the table is also something that is challenging but we have to work on as researchers. We

also have to understand how much people should use these interventions. What's the context and the individual characteristics influence at each stage of their usage?

And then finally, we have to have more interdisciplinary bridges because people in computing can't do this themselves. We need health behaviorists, we need social disparities researchers, medical informaticians, and also community members. We need to keep those bridges and build up those bridges and make them stronger.

Khari: So we kind of touched on this a little bit, but what techniques have you found useful to making sure that people have a voice at the table?

Katie: Right. To get a voice at the table some things that I like to do are to identify community leaders and to first, even before they come to a research meeting, I usually meet with them and talk to them about who else will be at the table, what expertise they bring, why it's important to our group. The other piece is making sure that they are comfortable with speaking up, so a lot of that comes from working with the community to understand.

The University of Michigan has a really great program. It's a couple of days long workshop where it will teach community members how to be part of a research intervention that I would love if we can model here at my own institution. The other part is not just empowering them to speak up, but to show them that you're listening, right? To be an active listener, which a lot of times we listen because we want to have a retort back, but to actually listen to what they're saying and say, "I hear you and what are your ideas of addressing this? And then here our ideas of addressing it." Then showing how it integrates into your follow up reports and to your follow up actions.

I think one of the big challenges is that a lot of research is not of interest to everybody. Like, one of the big challenges when I work with bringing someone to the table is the idea that, "Oh, we're going to show user study data you have to get ethics board training," and that's eight hours of online quizzes. It's not like, "Welcome to the team. Come take this eight hour quiz, you know?"

[Laughter]

Nothing says welcome to the team quite like that. So part of it is, ok you can't look at raw study data, but we can summarize it. How much should they be involved and to make sure that we are working on things that they're interested in, too.

Khari: Ok. That actually brings up a related question, as a researcher, what is the process to make sure you're using data in an ethical way and that the people giving you the data know what you're doing with it?

Katie: That's a really, really great question. So, in terms of the research process, one is that all of the researchers who work with human subjects have to take an exam. We use the CITI ([Collaborative Institutional Training Initiative](#)) exam, which is a standard exam that many other universities work through so that we understand people's rights and we understand the implications of this.

Then, once we actually pass those exams, if we want to do a study with humans there is a form that we fill out that talks all about how we interact with them, the data we collect, what we'll do with that data. Then part of this is we create an informed consent. If you've ever been part of a study, you've probably read an informed consent that outlines everything that we're going to collect, how long we're going to keep it, what we'll do with the data. Part of it too, in our interview process, in our protocols, we typically have a moment where we talk to people.

But I think a typical behavior when someone is in a study is, if I give you a two or three page document you may not necessarily want to read it…

[Laughter]

I'm saying you, but anybody may sign it and give it back to me and I'll say, "Do you have any questions?" And they typically say, "No."

[Laughter]

You should read those documents. There is some research going on now, I know, about people's understanding of what they signed and how we can make it more understandable. Then in terms of the study, what we typically do is, when we give people the technology or if we engage people in a study, we explain what's going on and how long we'll keep it. A lot of times, though...for example, with the Garmin study we had to let them know — it's not called the Garmin study, but when we worked with Garmin Technologies with older adults and pregnant people — we had to explain to them that Garmin will have a copy of the data, but we're downloading the data and here's how we'll use it, but Garmin will always have a copy of this data.

Likewise, I've done studies on Facebook. We have a method called the asynchronous remote communities method, it's kind of like a focus group, but it's on Facebook. It's a closed private group where we ask questions and people answer. But we have to remind them at the beginning and at the end, sometimes also in the middle, that all their answers, although it's in a private group, Facebook will have it. And then recently we learned not only will Facebook have it, but you can download all your data from Facebook if you want, and you can see your answers in that archive, too. It's like we have to be transparent, and we should be transparent with how we store their data, but then there's always that we don't know what the industry will do with that data.

Then the last part that my research team does is we typically, once we finish a study and we write a paper, we will share it with our participants if they choose to either follow us or be part of our Facebook groups or whatnot. And we will share papers and get feedback. Sometimes we get feedback before we submit it and then we get feedback after just to hear what they think of how we're presenting the data.

Khari: Ok. So are you typically working with systems that already exist like Facebook or Garmin, or do you ever develop your own internal systems to do these kinds of studies?

Katie: Yeah, both. We have...in my work when I'm working with larger populations — so those upstream interventions — we need to make sure that they are rugged and well tested and fully networked, so we typically use more commodity systems. But in the TAIPOR research with the older adults and the toolkits, we are actually designing our own toolkits where people can create their own own home sensing or on body sensing systems as they go. We've also created our own mobile phone apps to help people manage their nutrition. We kind of work with a range of either commodity systems or more prototype systems with smaller groups.

Khari: Ok, and let's say someone listening to this was like, "Wow, I didn't know this existed. I have seen this problem in my community. How can I get a health informatics researcher to study it?" What would you suggest that they do?

Katie: Right. That's a great question in terms of what should they do if they wanted to get involved? I think one way is, actually, if you see a research project that you're interested in, definitely contact the research team that's doing that research to see if they would be interested in deploying it elsewhere. When we have mobile phone technology we could do a research study...we could deploy it remotely. With toolkit systems it's a little bit more challenging. You'd have to send it, but it's still possible. So you can contact that research team to see if they're interested. Typically, we are interested in finding other populations to work with. If you have a problem in your

community and you are interested in it, then you can also contact researchers at a university. That's kind of cold calling. Sometimes it works with varying luck.

Another would be to contact researchers. You can contact [myself](#) and contact my colleague [Tiffany Veinot](#) — putting her on the spot here, but I think she would love that too. But you can contact researchers who are involved in these initiatives where we are working with community members. Then we would help either find someone in your local area who would be interested in working with that problem or, you know, depending on what the topic was, we may be able to do so.

[Challenges to Studying Usability of Technology Systems in the Wild - 20:50]

Khari: Ok. So let me ask you about a couple other of your projects before we wrap up. I know you've done some work on monitoring food intake. What are the big challenges to doing that?

Katie: So food intake, it just takes way too much time to monitor your food intake. I believe in computing we call it "eating your own dog food." Whenever we create these apps or systems I use them and I do exactly what I would expect participants to do. I am really bad at monitoring my food intake, even when I want to do it. Even when I'm working with a dietitian I'm bad at it, because part of it is that manual input of everything, right? So something has to give here. Either we're going to abstract what you eat and we're going to say, "Oh, I had a ham and cheese sandwich," or you're going to get every little bit of information. Like, "I had two tablespoons of mayo on my sandwich." I'm not going to measure out, I'm going to estimate if it has two tablespoons that I don't want to be judged.

[Laughter]

So the input is a real challenge. The other thing is that you can say, "Oh, you can take pictures," right? Like we all have phones that can take...well, most of us have phones that can take pictures now, but vision recognition is really difficult. We're not there yet. You know, it's hard to know what's exactly on your sandwich when you have it.

The other thing is, is we're not sure how big it is. Sometimes we need what's called a [fiducial marker](#). We put a quarter next to it. You know how big a quarter is, so I can get a sense of how big it is. There's some studies that show you take a picture from the top and both sides, so I know, like, what is it. But again some things are easier to tell than

others. A bowl of cereal? Sure. Your favorite burger? It's going to be hard to tell what's on there. It's not quite there.

The other part is the actual feedback and making sure that people get the data and they know what to do with it. A standard example is, in my own research when we were working with a low socioeconomic population, the people were Hispanic, and they were showing me they would get….they had a whole drawer full of these pamphlets that would tell them healthy family eating behaviors. And the mom was explaining to me how it said to bake stuff. Her family loves [sopapillas](#), she decided to try to bake them — of course they were terrible. Sopapillas should not be baked. And she's like, "Now my family is hungry and I ruined it, so I just decided to not bake anymore."

So you can't just be like, "Bake this." You have to think about what's actionable. One of the systems that we use, we work with a nutritionist, because I said, "You know, if someone puts in that they just eat a bag of potato chips, I don't want to tell them to go eat an apple, right?" So we were like, "OK, you ate a bag of potato chips, now try baked potato chips. Is it the salt or is it the crispiness? Ok, here…" And we just, kind of, slowly made recommendations based on their craving instead of just saying you should eat an apple now.

The other challenge with food intake is confirmation bias. With confirmation bias...an example, when we were working with the low literacy people with end-stage renal disease, the renal dietician was telling the participant to stop drinking Big Gulps of Coke. And what he heard was Coke is a dark color, I should drink...because she was like, you should try a cup of water. And what he heard is I shouldn't drink something dark, I should drink something light. So he started drinking Big Gulps of Sprite. But the big problem here with people with end-stage renal disease is you should only have like a liter of water a day. So the Big Gulp, the size is the problem.

When he used our system, he scanned the Big Gulp, it showed him red, it showed him way over his liter. And he was like, "Oh, I can't drink a Big Gulp. I can drink a can of Coke, but not a Big Gulp."

And the dietician was like, "I've been telling him this all along," but he had his confirmation bias and then he was like, "Oh, it's the color, not the not the size." And it wasn't until he got the actionable feedback that he was like, "Oh, it's the size." So we've got to make sure we know what people are thinking.

Khari: Ok, yeah, I could see how that's a challenge. So outside of, like, food monitoring what are other challenges to studying the usability of technology systems in the wild?

Katie: Yeah, a lot of our stuff is in the wild. We don't really do a lot of research in the lab, and basically everything that can go wrong will. People may have different living environments. We do a lot of testing before we actually put it in users' hands. We test in our own homes. We test in friends' homes. And what we've found is, you can you can test it in the lab, you can test it in your house, but then the very first participant you go to will have a house completely made of stone that doesn't allow wireless signals to go through.

The other thing that we've had go wrong is like the Internet may go out. Then you have to be able to make sure that you can store all your data there. You have to make sure that you can configure systems and make sure that they fail gracefully, but not lose all of your data to run the study. The other thing, too, is that in the wild people may use systems differently. If I talk to someone, I'll say to them, "Are you the only one who uses your phone?" You typically say, like, "Yeah, I'm the only one who uses my phone." But the next thing we know is that, as we're looking at app data, they're working and yet their phone is in a different location based on our study and then we'll find out, "Oh, right my daughter really liked the app, so I just let her use it."

[Laughter]

And it's like, "Oh, that's a different participant." People may not use technology the way you think that they should or the way the protocol said, they can use any way they want. And then accidents always happen and sometimes it destroys the tech in your study. We've had incidences where we had sensors deployed in the city environment and then a storm came through and two of them got destroyed. People lose cell phones. One of our sensor systems, we had an issue with a rodent that chewed on the sensor.

[Laughter]

So you also never know what kind of home or environment you're going to go into. We thought the sensor was malfunctioning. We went in and we just had a bunch of rodent dropping all over it and that was blocking the sensor. So we ditched the whole thing, we weren't going to clean that up and start it up again. So I think the challenges are just like, anything that can happen will happen and you just never know. So you try to be as prepared as you can be, but understanding that you're going to have to be super flexible and fix it quickly.

Khari: Yeah, that's funny. What role do you see social media playing sort of in addressing health disparities or just helping people with their health in general?

Katie: Yeah, so in terms of social media, I think there's a lot of ways that social media can help, especially with showing information about health practices or about tips and tricks, as long as they're kind of short and you can easily digest them. I think social media is really good as long as it's authoritative. It's a really great mechanism to get information out there quickly. It's not going to be a ton of information. It's not going to be comprehensive. But if you have these short, sharp pieces you can get them out there.

I think, though, one of the main challenges is that you never know what other social media or feeds people are consuming. So as much as it's easy for us to put good information out there, it's also easy for anybody to get information. To understand what information they're getting is always a challenge.

Khari: I know I was reading... I don't remember who wrote this and now I can't find the link, but you shared a paper, I think it was about menopause, and they were studying a subreddit that was dedicated to this and how and how people are interacting on that subreddit. I thought that was pretty interesting.

Do you know which study I'm talking about?

Katie: I think you're talking about [Dr. Amanda Lazar](#)'s paper. Is this the paper? It's the [*Parting of the Red Sea*](#)?

Khari: Yes.

Katie: Yes. I think one of the challenges with social media and how people interact with it, especially in this case with menopause and also perimenopause, is that there's not a whole lot of information out there. Especially around women's health there's a whole bunch of like...people don't share information. People are told that it's not a big deal, so the only way to get it is through these social connections either through talking to people you trust or to go to online media to get the information.

I think this is a way for the medical community to see where gaps are and what alternatives people are turning to for information. And it's also a great plan to kind of get data to understand what we need to address and create information for people. I think

the menopause and the perimenopause communities are a really great area to study and to help.

[Proactive Health Informatics RU - 31:00]

Khari: And what is the [proactive health informatics REU](#)?

Katie: The proactive health informatics REU — REU stands for research experience for undergraduates — this is a National Science Foundation program where we bring in ten undergraduates for eight weeks to do research with researchers. It's a really great experience, especially for people who aren't sure what research is or are kind of interested, perhaps, in research or grad school. It's a great way to kind of see if it's for you. Just kind of try it out.

Khari: So, if someone's interested how can they apply?

Katie: Right. So the National Science Foundation has a [website of all the REUs](#). You can either think of a research experience in terms of what area you're interested in. It's not just computing, it can be any type of research that is funded through the National Science Foundation. Then you can apply, typically, on their website.

The application should be coming online soon, typically it's October, November, and usually deadlines are January through March. They're fairly competitive, but most REU sites are really committed to diversifying computing research; so, you know, you should just try to apply.

[Laughter]

The other part here is that you can either look at the research area you're interested in or the part of the country that you're interested in. There are even some international REU experiences or you can just look at the universities that you're interested in. You can spend a summer at that university. There's all different ways to kind of think about the research experience for undergraduates.

[Dream Health Informatics Research Center - 32:50]

Khari: Fnal question, if you were to build your dream health informatics research center, what would it be? What would it do? Money is no obstacle.

Katie: I love this question. I love this question and cringe. I think if I listen to myself in 10 years, I'll be like, "Ugh, that was so naive."

[Laughter]

But this is my current vision of the center. We would have a group of like eight distributed satellite centers in communities all across the country. I'm saying eight it could be more, but I think that eight is far enough to start up with. We want centers in urban and rural and suburban areas with varying demographics. And we would have community members who are integral parts of those research centers, kind of trained like from [the program at] the University of Michigan, but it would be Indiana University's iteration of that program to make sure our community members are actively engaged. It would be like laypeople are truly part of that research team.

We would definitely have a team with social scientists and STEMresearchers and policy wonks so we can get those upstream interventions going. And we would have the community members identify the projects that are most important to them with the idea that we would build out over years so that researchers could also make larger contributions to their own areas. But this would also take a ton of time to recruit our collaborators, because I'd really want people who are passionate about improving the lives of everyone, not just hardcore scientific contributions.

I'd want kind of like a flat hierarchy. I know that doesn't really make sense, but in terms of leadership, we would all be working together over our eight distributed satellite centers, it would be wonderful and we would have well compensated graduate and postdoctoral researchers. I think a big thing right now for graduate students is making sure that they have living wages, making sure they have health insurance, making sure that they're not being knocked down by fees and their dependents are well taken care of. So they would be well compensated graduate and undergraduate researchers who would be working on projects and also doing regular community outreach.

It would be a lot of work, but without the community outreach component, you're losing a lot of the context. Then the other part of this project, besides there being community members involved, is that we would have teachers working with our group and we would compensate them at a researcher level not at a public teacher level. They would spend summers working on projects that are interesting to them, and then we would have the entire team helping them create modules that they can bring back to K-12 education so that children in the communities can understand what's going on. We just want all the levels of people working together.

Khari: Yeah, that would be exciting. So if someone from NSF or NIH listens to this, you know who to call.

[Laughter]

Katie: That's right.

Khari: Any final thoughts before we sign off?

Katie: Yeah. One of the things I think is really important here is, I want to make sure that researchers in computing, that we are working on real-world problems that are going to make an impact. We really have to make sure that we're going out to those community members to see what they need, not just what we think they need. Then we have to keep revisiting to make sure that those needs are really being met with the technology we're creating. And it's going to be a challenge. We're going to have to look at those contributions.

Then to kind of policymakers or grant funding agencies is to understand that these kinds of connections take time. If I'm addressing the community's challenge, I may be making slower progress on my scientific contributions, but it will be big. You know, once we get the community buy in then we'll be able to do those upstream interventions. So we definitely need to kind of think longer term for funding and funding models and expectations.

Khari: Sounds good. Well, thanks for taking the time to do this interview, Katie. Have a good day.

Katie: Thank you.

[Outro - 37:11]

Khari: That's it for my interview with Katie Siek. We'll be back soon with new episodes. Until then, remember to, like, subscribe and rate us five stars wherever you get your podcast. Learn more about the work of the CCC on our website at [cra.org/ccc](cra.org/ccc) and find us on social media to stay up to date on our latest activities.

Until next time. Peace