May 2017

Executive Summary

BD4BC

BIG DATA FOR BREAST CANCER

Table of Contents

Summary

In October 2015, Susan G. Komen® convened *BD4BC: Big Data for Breast Cancer* with generous support from the Robertson Foundation. The intent was to explore the opportunities and challenges of incorporating Big Data applications into oncology research and clinical care, using breast cancer as a "case study" or "proof of concept." The conversation at BD4BC focused largely on the biomedical and clinical research that is taking place and how it would benefit from Big Data applications. In addition to the different actions that Komen has taken following BD4BC (see Progress Report from October 2015), participants also felt that Komen should convene scientists and those who "hold the keys" to Big Data (e.g. payers, Electronic Health Record [EHR] providers, patients, policy makers) for further input and discussion.

Komen acted on this suggestion by using the unspent funds from the *BD4BC* to convene *BD4BC – West Coast Conference (BD4BC\WC)* to continue the conversation about Big Data, defined as the integration of EHR, administrative databases, large data repositories, and genomics and other –omics data. As mentioned in the October 2016 Progress Report, Komen first assembled a Planning Committee:

- Amy Abernethy, M.D., Ph.D.; Flatiron Health
- Cheryl Jernigan, CPA, FACHE; Komen Advocate in Science and Scientific Advisory Board
- Mia Levy, M.D., Ph.D.; Vanderbilt-Ingram Cancer Center and Komen Scholar
- George Sledge, Jr., M.D.; Stanford University and Komen's Chief Scientific Advisor
- Crystal Valentine, Ph.D.; MapR Technologies
- Nikhil Wagle, M.D.; The Broad Institute of MIT and Harvard and Dana-Farber Cancer Institute

Building on the knowledge gathered during *BD4BC*, Komen and the *BD4BC\WC* Planning Committee structured *BD4BC\WC* to take a deeper dive into the informatics and analytics that are currently in use to curate large amounts of data, gather patient-derived lifestyle and health-related data, and machine learning systems that are able to integrate large amounts of data from multiple sources.

Set in the heart of Silicon Valley, BD4BC\WC was held on February 23-24, 2017 at the Quadrus Conference Center in Menlo Park, CA. The goal of this meeting was to better understand current capabilities of Big Data applications and to encourage the development of multidisciplinary collaborations that will work together to demonstrate the feasibility of applying Big Data technology to several breast cancer-focused use cases including development

of evidence-based decision support to improve breast cancer treatment, quality improvement of health care delivery, and basic discovery to drive research.

Approximately 50 experts (Appendix A) from 40 organizations, both non- and for-profit, participated in an inclusive meeting and lent their diverse expertise to answer a series of challenges and questions:

- How do you envision the use of Big Data will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?
- What are some of the biggest challenges that will need to be addressed to realize that vision in the next decade?
- What could patient advocates and patient advocacy organizations do to help overcome those challenges?
- What current uses/features of Big Data are or have the potential to be of highest benefit to breast cancer patients?
- What specific uses/features of Big Data are or will be able to address reducing breast cancer deaths? Specifically addressing deaths due to metastatic breast cancer and/or to breast cancer disparities?

To best leverage the participants' expertise and outline the most promising breast cancer applications of Big Data, the agenda for *BD4BC\WC* was developed around three main topics:

1. Data infrastructure: How is Big Data structured? How is it accessed? By whom? What are the best practices to ensure data can be shared, integrated and analyzed for multiple purposes?
2. Research: The latest advances in research using Big Data, whether it is genomics, proteomics or other "omics." Examples highlighting the many ways in which Big Data drives breast cancer research, from generating hypotheses to creating the tools that will help design tomorrow's therapies.
3. Clinical applications: The current efforts to harness Big Data to provide the solutions needed to overcome the challenges faced by breast cancer patients.

Each of these sessions featured two panelists, who gave short, TED-style talks about their area of expertise, and a facilitator selected from the planning committee (Appendix B).

Throughout the discussions, participants focused on defining specific roles for Komen to play in ensuring that Big Data benefits breast cancer patients:

- With *BD4BC* and *BD4BC\WC*, Komen demonstrated that it is uniquely positioned to convene the right mix of stakeholders to tackle the challenges of delivering the

promises of Big Data to breast cancer patients. Attendees mentioned that they had participated in many Big Data meetings, but these meetings had neither the right mix of expertise convened nor the richness of the discussions heard at *BD4BC\WC*.

- Komen has a track record of advocating for patients. It can make one of its advocacy priorities to encourage access to Big Data and ensure that policies are in place to guarantee privacy and security of patients' data as well as appropriate reparations should a breach occur.
- Komen can lead by example by requiring researchers to share data generated with Komen funding.
- Komen can serve as an honest broker for patients' data. Patients generally don't trust for-profit companies with their data – an organization like Komen would be seen as a nonpartisan broker that could partner with appropriate data service provider(s) to develop or expand a platform where data can be safeguarded, with access provided to the stakeholders who will provide the most benefits to breast cancer patients.
- As a grassroots organization, Komen can also leverage its wide network of influence to further educate patients and the public about Big Data and encourage data donations.
- Komen can consider providing programs to address the barriers to participating in clinical trials, such as financial help to cover participants' transportation and lodging.
- Komen can once again be a trendsetter by creating a research program that will develop a workforce fluent in informatics and biology – the only way seen by the attendees for Big Data to be fully harnessed to advance our knowledge of breast cancer and to leverage that knowledge into actionable roadmaps to curing breast cancer.

Outcomes

While additional conversations with the *BD4BC\WC* Planning Committee and Komen's Scientific Advisory Board are needed to define the next steps, the *BD4BC\WC* meeting has already resulted in several outcomes:

- *Reframed knowledge:*
  - *Barriers:* In order to address the barriers to harnessing Big Data, we must first understand what they are and are not: These barriers are not technologic in nature, but social, legal and economic.
    - Technology exists that can aggregate and make sense of unstructured data from multiple sources, but barriers still exist that make data sharing and aggregation challenging. However, several pilot projects were presented that show promise in overcoming these barriers.
    - Participants noted that continuing to break these barriers will require incentives - both rewards and penalties.
  - *Intentional data:* It was clear from the discussions that the goal of Big Data is not to relentlessly and aimlessly amass information. Oncologists at *BD4BC\WC* warned against a trend toward over-structuring medical data, leading the doctors to spend more time entering data into electronic medical records than attending to breast cancer patients. As one attendee summarized: "saving doctors' time will save patient lives."
- *Media coverage: BD4BC\WC* was a working meeting. To ensure an open environment where participants could speak freely, including proprietary content, media coverage was limited. There were, however, several media outcomes from the meeting:
  - *Written pieces:*
    - Susan G. Komen Convenes Second Symposium to Leverage Big Data in the Fight Against Breast Cancer (press release).
    - MapR Joins Susan G. Komen in the Mission to End Breast Cancer (press release)
    - Big Possibilities with Big Data in Breast Cancer (blog post)
  - *Social media:* Komen and attendees brought the conversation online by using the #BD4BC hashtag, which was also used during the first meeting (*BD4BC*). Komen is planning a social media strategy to keep the attendees and the public engaged, informed and updated on the progress made with harnessing Big Data for breast cancer patients.

- *White Paper:* The draft white paper summarizing the *BD4BC* initiative is being updated to reflect the discussions at *BD4BC\WC*. When finalized, the white paper will be made available to the public through publication in a peer-reviewed journal or self-publishing on Komen's website (komen.org).
- *Potential Partnerships and Resources:* Attendees all agreed that Komen was the right organization to drive the conversation and the right partner with which to take the necessary actions to fully achieve the impact of Big Data for breast cancer patients. Virtually all attendees expressed their support to helping Komen reach that goal. Komen continues to pursue additional partnerships and outside funding for pilot programs including:
    - CLOUD, Inc. – The Consortium for Local Ownership and Use of Data: CLOUD, Inc. is developing a new language, called CTML. CTML will allow relevant pieces of data to be shared and pulled into larger datasets without compromising privacy or security. Gary Thompson, founder and CEO of CLOUD, Inc., spoke at BD4BC\WC and expressed interest in working with Komen on a joint project to bring this vision to breast cancer patients and health care providers. Komen staff and Scientific Advisory Board members continue to meet with Mr. Thompson to explore this opportunity.
    - Perthera: Perthera is a precision medicine company that aggregates genomic data and formulates data-driven treatment plans for patients. Representatives from Perthera attended BD4BC\WC and have offered to work with Komen on a pilot project to offer genomics-driven treatment plans to breast cancer patients. The proposed project was presented to Komen's Scientific Advisory Board on May 8, 2017. The Scientific Advisory Board requested some additional information from Perthera, which is currently under consideration.
    - Tempus: Tempus is a Big Data technology company that is building a library of molecular and clinical data to facilitate data-driven healthcare. Tempus' Chief Medical Officer, Dr. Gary Palmer, attended BD4BC\WC and their Founder and CEO, Eric Lefkofsky has had conversations with Komen's staff and Chief Scientific Advisors about a potential collaboration to aggregate data from Komen's research grants and programs. Conversations are ongoing to ensure that the project affords the highest benefit to breast cancer patients.
    - MapR Technologies: MapR Technologies was represented on the planning committee for BD4BC\WC by Dr. Crystal Valentine, Chief Technology Officer. MapR offers a converged data platform that can access and analyze data in

any format. MapR has expressed interest in supporting Komen's potential "Big Data Exchange", a training program to cross-train biologists/oncologists in Big Data technology and Big Data scientists in the biology of breast cancer in order to develop a workforce fluent in Big Data applications for breast cancer research and care.

Next Steps

The conversation at *BD4BC\WC* outlined many opportunities for Komen to drive efforts in research and health care that will effectively harness Big Data for the benefit of breast cancer patients. Now that *BD4BC\WC* is completed, focus has shifted to defining which opportunities to prioritize and how to best leverage Komen's assets for a Big Data initiative. The *BD4BC\WC* Planning Committee members have agreed to continue discussing those opportunities and help Komen's Scientific Advisory Board develop the strategy for a Big Data initiative. These discussions will also highlight the resources and partnerships that will be needed to deliver that strategy.

Along with forming that strategy, Komen will continue reaching out to stakeholders in the Big Data arena. All contacts that Komen established through *BD4BC* and *BD4BC\WC* expressed interest in being involved in Komen's efforts going forward. Growing this contact list will accomplish two goals: 1) allow Komen to leverage the right assets to execute its Big Data initiative; and 2) ensure that Komen's Big Data initiative is shared within the broader community.

Komen is engaging its Scientific Advisory Board in discussions about ways to support research involving Big Data. While discussions are ongoing, the Scientific Advisory Board recommended the following for implementation during Komen's fiscal year 2018 (April 1, 2017 – March 31, 2018):

- Require data sharing for all Komen-funded research projects
- Develop and implement a training program designed to create a workforce fluent in both data science and cancer biology

In addition to a strong interest in Big Data applications in research and health care, the time is right to establish a successful Big Data initiative that will truly inform research and improve outcomes for all cancer patients. Once Komen's strategy is in place, we are confident that we will be able to secure the necessary resources to be successful in this effort – ultimately unleashing the full promise of Big Data for breast cancer patients.

Appendix A: BD4BC Participant List

First Name	Last Name	Degrees	Institution/Org
Amy	Abernethy	MD, PhD	Flatiron Health
Preeti	Bajaj	PhD	Genentech
David	Barron	MBA, JD	CLOUD, Inc.
Ashley	Blanchard	MS	Perthera
Daniel	Buchmueller		Flatiron Health
Kenneth	Buetow	PhD, FACMI	Arizona State University
Alessandra	Cesano	MD, PhD	NanoString
Bin	Chen	PhD	University of California – San Francisco; California Initiative to Advance Precision Medicine
Kellie Jo	Ciofalo	MBA	Flatiron Health
Deborah	Collyar		Komen Advocates in Science (AIS)
Kathy	Colon	MBA, MPH	IBM-Watson
Bob	Cook-Deegan	MD	Arizona State University
Gini	Deshpande	PhD	NuMedii
David	Dolton		Perthera
Sandy	Finestone	PsyD	Komen AIS
Elizabeth	Forner		Eisai
Annie	Gallagher		Redox Engine
Jianjiong	Gao	PhD	cBIO Portal; Memorial Sloan-Kettering Cancer Center
Melissa	Goldstein	JD	George Washington University
Robert	Grossman	PhD	Genomic Data Commons
Jonathan	Hirsch		Syapse
Katherine	Hoadley	PhD	UNC Chapel Hill; The Cancer Genome Atlas
Cheryl	Jernigan	CPA, FACHE	Komen AIS; Komen Scientific Advisory Board
Russell	Knoth	PhD	Eisai
George	Komatsoulis	PhD	CancerLinQ
Shefali	Kumar	MPH	Evidation Health
Mark	Lee	MD, PhD	GRAIL
Mia	Levy	MD, PhD	Vanderbilt University; Komen Scholar
Tony	Loeser	PhD	Syapse
Joshua	Mann		Share for Cures
Talia	Moyal		Oracle
Dale	Muzzey	PhD	Counsyl
Theresa	Neil	MBA	Theresa Neil Strategy & Design
Gary	Palmer	MD, JD, MBA, MPH	Tempus

First Name	Last Name	Degrees	Institution/Org
Emanuel "Chip"	Petricoin III	PhD	Perthera; George Mason University
Charles	Roberts	MD	Freenome
Alina	Salganicoff	PhD	Kaiser Family Foundation
Carol	Sanders	MA, FACHE	Project Data Sphere
Nigam	Shah	MBBS, PhD	Stanford University
Steve	Shak	MD	Genomic Health
Asim	Siddiqui	PhD	NuMedii
Gaurav	Singal	MD	Foundation Medicine
George	Sledge	MD	Stanford University; Komen's Chief Scientific Advisor
David	Szekeres	JD	Heron Therapeutics
Gary	Thompson	MBA, JD	CLOUD, Inc.
Crystal	Valentine	PhD	MapR Technologies
Nikhil	Wagle	MD	The Broad Institute of MIT and Harvard; Dana-Farber Cancer Institute

BD4BC\WC

BIG DATA FOR BREAST CANCER — WEST COAST CONFERENCE

February 23-24, 2017

susan g. komen.

#BD4BC

komen.org/bd4bc

Presented by Susan G. Komen®, with support from

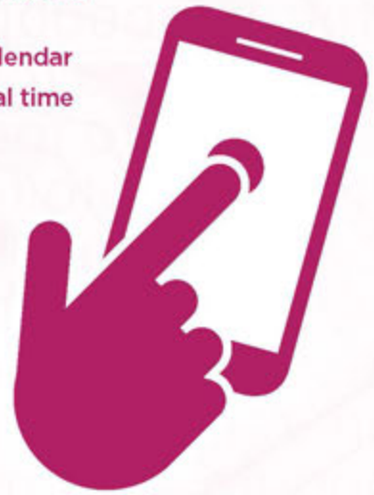
ROBERTSON FOUNDATION

Komen is continuing the big data conversation by convening the Big Data For Breast Cancer — West Coast Conference (BD4BC\WC) to take a deeper dive into informatics and analytics that are currently in use to curate large amounts of data, gather patient-derived lifestyle and health-related data, and explore machine learning systems that are able to integrate large amounts of data from multiple sources. By focusing on these systems and their capabilities, we hope these capabilities will be leveraged for breast cancer applications.

BD4BC\WC Has Gone Mobile!

Download the official mobile app of #BD4BC and maximize your meeting experience:

- Search **BD4BCWC** in Apple, Android, Blackberry and Windows app stores!
- View/add agenda sessions to personal calendar
- Receive meeting alerts and updates in real time
- View attendee directory



General Meeting Information

Location
Quadrus Conference Center, 2400 Sand Hill Road, Menlo Park, CA 94025.
Free self-parking available at Quadrus.

Conference Media Policy
Komen's Communications staff will be present at the meeting to conduct interviews and document the meeting. Content will be recorded and may be posted on komen.org/BD4BC following the meeting. If you do not wish to be on video or photographed please stop by the registration desk to make arrangements.

No Smoking
In keeping with Susan G. Komen's policy and our vision of a world without breast cancer, the BD4BC\WC meeting is a strictly nonsmoking event.

Shuttle Information

Shuttles will be provided between the Westin Palo Alto and Allied Arts Guild on Thursday evening and Quadrus Conference Center on Friday. Please reference the schedule below.

Thursday, February 23

4:45 p.m. — First shuttle will depart from the Westin Palo Alto for Allied Arts Guild; second shuttle will depart at 5:00 p.m.

Shuttles will also be available immediately following the conclusion of dinner for transport back to the Westin Palo Alto.

Friday, February 24

7:45 a.m. — First shuttle will depart from the Westin Palo Alto for Quadrus Conference Center; second shuttle will depart at 8:00 a.m.

Shuttles to SFO, SJC and Westin Palo Alto will be outside the Quadrus front entrance.

The Impact of a Promise

Susan G. Komen® is the world's largest breast cancer organization, funding more breast cancer research than any other nonprofit outside of the federal government while providing real-time help to those facing the disease.

Komen has set a Bold Goal to **reduce the current number of breast cancer deaths by 50 percent in the U.S. by 2026.** Since its founding in 1982, Komen has funded more than $920 million in research and provided more than $2 billion in funding to screening, education, treatment and psychosocial support programs serving millions of people in more than 30 countries worldwide. Komen was founded by Nancy G. Brinker, who promised her sister, Susan G. Komen, that she would end the disease that claimed Suzy's life.

BD4BC\WC Planning Committee:

Amy Abernethy, M.D., Ph.D.
Flatiron Health

Cheryl Jernigan, CPA, FACHE
Komen Advocate in Science and Scientific Advisory Board

Mia Levy, M.D., Ph.D.
Vanderbilt-Ingram Cancer Center and Komen Scholar

George Sledge, Jr., M.D.
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Crystal Valentine, Ph.D.
MapR Technologies

Nikhil Wagle, M.D.
The Broad Institute of MIT and Harvard and Dana-Farber Cancer Institute

BD4BC\WC AGENDA | FEBRUARY 23-24, 2017

Thursday, February 23

Allied Arts Guild, 75 Arbor Rd, Menlo Park, CA 94025

5:00 p.m. - 6:00 p.m. **Reception**

6:00 p.m. - 8:00 p.m. **Welcoming Remarks & Dinner**

Friday, February 24

Quadrus Conference Center & Catering, 2400 Sand Hill Rd, Menlo Park, CA 94025

8:00 a.m. – 8:30 a.m. **Registration & Breakfast**
- **Conference Room Q1**

8:30 a.m. – 9:00 a.m. **BD4BC\WC: Overview & Goals**
- **Conference Room QCC**

9:00 a.m. – 10:45 a.m. **Session #1: Data Infrastructure**
Facilitator: George Sledge, Jr., M.D. (Stanford University)
Speakers:
- Gary Thompson, J.D., M.B.A. (CLOUD, Inc.)
- Crystal Valentine, Ph.D. (MapR Technologies)

Facilitated Group Discussion (all participants)
- **Conference Room QCC**

10:45 a.m. – 11:00 a.m. **Break**
- **Conference Room Q1**

11:00 a.m. – 12:30 p.m. **Session #2: Research**
Facilitator: Mia Levy, M.D., Ph.D. (Vanderbilt-Ingram Cancer Center)
Speakers:
- Amy Abernethy, M.D., Ph.D. (Flatiron Health)
- Nikhil Wagle, M.D. (Broad Institute/Dana-Farber Cancer Institute)

Facilitated Group Discussion (all participants)
- **Conference Room QCC**

12:30 p.m. – 1:30 p.m. **Lunch**
- **Deck**

1:30 p.m. – 3:00 p.m. **Session #3: Clinical Applications**
Facilitator: Nikhil Wagle, M.D. (Broad Institute/Dana-Farber Cancer Institute)
Speakers:
- Mia Levy, M.D., Ph.D. (Vanderbilt-Ingram Cancer Center)
- Gaurav Singal, M.D. (Foundation Medicine)

Facilitated Group Discussion (all participants)
- **Conference Room QCC**

3:00 p.m. - 4:00 p.m. **Wrap-Up & Closing Remarks**
- **Conference Room QCC**

Susan G. Komen® Scientific Advisory Board

Chief Scientific Advisors

George Sledge, Jr., M.D.
Stanford University School of Medicine
Stanford, CA

Eric Winer, M.D.
Dana-Farber Cancer Institute
Boston, MA

Scientific Advisory Board Members

Carlos Arteaga, M.D.
Vanderbilt-Ingram
Cancer Center
Nashville, TN

Myles Brown, M.D.
Dana-Farber Cancer Institute
Boston, MA

Powel Brown, M.D., Ph.D.
The University of Texas
MD Anderson Cancer Center
Houston, TX

Karen Gelmon, M.D.
British Columbia Cancer Agency
Vancouver, Canada

Cheryl Jernigan, CPA, F.A.C.H.E.
Advocate in Science
Komen Greater Kansas City
Kansas City, MO

Amelie Ramirez, Dr.P.H.
The University of Texas
Health Science Center
San Antonio, TX

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Melissa Maxfield

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Meghan Shannon
Affiliate Board Representative

Trish Wheaton

Linda Wilkins

Angela Zepeda

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Follow Along on Social Using #BD4BC

We encourage you to engage with Komen and other attendees by joining the BD4BC\WC social conversation, using **#BD4BC**.

Share inspiring mission moments, interesting and educational facts, and kudos to those making a difference.

#BD4BC

komen.org/bd4bc

BD4BC\WC

BIG DATA FOR BREAST CANCER — WEST COAST CONFERENCE

OUR BOLD GOAL

Reduce the current number of breast cancer deaths by

50%

in the U.S. by 2026.

susan g. komen.

komen.org

BD4BC\WC

BIG DATA FOR BREAST CANCER–WEST COAST CONFERENCE

February 23-24, 2017

Menlo Park, CA

with support from ROBERTSON FOUNDATION

BD4BC\WC: Questions & Challenges

- How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?
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- What current uses/features of “big data” are or have the potential to be of highest benefit to breast cancer patients?
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BD4BC\WC

BIG DATA FOR BREAST CANCER–WEST COAST CONFERENCE

Session 1

Data Infrastructure

Moderator: George Sledge, Jr., M.D.
(Stanford University; Komen's Chief Scientific Advisor)

BD4BC\WC: Questions & Challenges

- How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?
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BIG DATA FOR BREAST CANCER–WEST COAST CONFERENCE

Session 2

Research

Moderator: Mia Levy, M.D., Ph.D.
(Vanderbilt-Ingram Cancer Center; Komen Scholar)

BD4BC\WC: Questions & Challenges

- How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?
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LET'S SOLVE THIS PROBLEM BY USING THE BIG DATA NONE OF US HAVE THE SLIGHTEST IDEA WHAT TO DO WITH
TOM FISH BURNE
© marketoonist.com

BD4BC\WC

BIG DATA FOR BREAST CANCER–WEST COAST CONFERENCE

Session 3

Clinical Applications

Moderator: Nikhil Wagle, M.D.
(The Broad Institute of MIT and Harvard; Dana-Farber Cancer Institute)

BD4BC\WC: Questions & Challenges

- How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?
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BD4BC\WC

BIG DATA FOR BREAST CANCER–WEST COAST CONFERENCE

Wrap-Up Session

Moderator: George Sledge, Jr., M.D.
(Stanford University; Komen's Chief Scientific Advisor)

BD4BC\WC: Questions & Challenges

- How do you envision the use of “big data” will lead to a better understanding of breast cancer, improve delivery of care, optimize treatment decision making, etc.?
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Keep the conversation going.

Comments, suggestions, follow-ups?

Email Jerome Jourquin at
JJourquin@komen.org