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The Ribbon

A Newsletter of the Cornell University
Program on Breast Cancer and
Environmental Risk Factors
in New York State
(BCERF)



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BCERF Completes Field Testing of the Five-Module Tool Kit

Juliette Ramírez, BCERF Health Educator

Field Testing the Five-Module BCERF Tool Kit

The premise behind the BCERF Tool Kit is that practical breast cancer risk reduction messages can and should be integrated into the real lives of people living throughout the state of New York. Therefore, content addresses situations at work, home, and in the community, and has a multi-generational component wherever appropriate. Another basic tenet is that Cornell Cooperative Extension (CCE) and other community educators are "field experts" in the area of educating their own communities. Whenever possible, we integrated the expertise of these educators into the writing, presentation and evaluation of the modules. The Tool Kit maximizes use of existing education networks and groups, such as EFNEP (Expanded Food and Nutrition Program), NYS IPM (Integrated Pest Management program) and community clubs. This made the field testing process more attractive, practical and efficient for busy educators, and demonstrated how the modules could be integrated into existing programming.

The development and field testing process was funded by the New York State Departments of Health and Environmental Conservation. We would like to take this opportunity to share our process and results with *Ribbon* readers, as we believe we have created and carried out an efficient and replicable evaluation of materials, that provided rich and useful feedback. We thank our field testers!

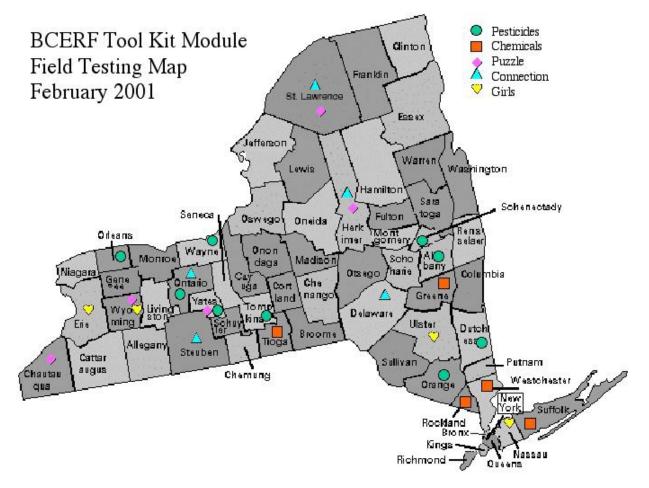
Overall Results: A First Look

A total of 630 participants attended presentations at 57 sites spanning 23 counties (see map on next page). We collected 536 quantitative participant evaluations and 429 forms providing qualitative feedback from participants.

In-depth qualitative data from facilitators and participants was more important to this process evaluation than large participant numbers, so we set modest goals for numbers of participants. We received detailed feedback from facilitators for every presentation, and met our participant goal with three of the modules.

Just a few items characterizing overall results include:

- 91% of participants reported they knew more about the topic as a result of the program.
- 90% of participants responded that they had a better understanding of their role in reducing breast cancer risk as discussed in the session.



• 82% of facilitators responded that they would offer their program again.

We have a wealth of information from participants, who offered comments such as:

"I learned safety precautions and alternatives for household chemicals."

"[I think differently about] how I look [at] nutrition. I was reminded of the strong link between nutrition and exercise. [The facilitator] made me remember that diet and exercise need not be painful and can be a great motivator for girls."

"Great ideas for my family and my students."

Likewise for facilitators, who were very generous with their time in describing their thoughts about the materials:

"Healthy eating and exercise components went well. Need to be reinforced because they are much lacking in our rural community." "[I] definitely would give out the BCERF handouts.... Actually I would do everything as the program states. I thought it was a great program."

"This group received well the [information] about the puzzle of breast cancer. I would like the puzzle blown up, perhaps in color, to make a great instructional tool."

"My Attitudes Inventory generated some excellent discussion.... [A] great tool to initiate a discussion and get the group comfortable."

Module by Module: What Did We Learn?

• Talking About Pesticides at Home and in the Neighborhood and Talking About Pesticides With Your Customers are two parts of a module aimed at helping landscape professionals and their customers communicate more effectively about pesticide use in home landscaping. Either the public or the professional part of this module was tested in Tompkins, Dutchess, Wayne, Orleans, Orange, Ontario, Yates, Schenectady and Albany counties. Public audiences included many

Master Gardeners, while farmers and local nursery association leaders were among participants in the professional presentation. Most presentations took place at the CCE office, and a popular one was held in a local restaurant. This module is based on a slide show.

More facilitators chose to offer the public program rather than the professional program. We realized that this is because certified pesticide applicator training is a very specific responsibility of certain extension educators, many of whom did not learn of this field test. Through other activities we know with certainty that the type of material in Talking About Pesticides is relevant and appropriate to recertification training, and we will need to produce and market the professional part of the module accordingly. Facilitators had a range of success with this module, from very strong and positive programs, to less successful ones, with most being fairly strong. We are working closely with the NYS IPM program in analyzing results in order to produce the module in a way that works best for educators. Educators are very clear about the need for this type of programming in communities. The communication issues, the legal issues, and label-reading were all areas considered critical. Many participants and facilitators want to see more elaboration on the connection between pesticides and breast cancer, or health in general, integrated into this module. (See Pieces of the Puzzle below, an adaptation of which will be included in any Tool Kit order.)

• Talking Around the Table: Chemicals in the Home is aimed at helping low income families identify, use, and store chemicals safely in their homes and gardens. This module was presented in Suffolk, Rockland, Greene, Westchester and Tioga counties. Audiences for the field test included EFNEP groups in several counties, a parenting group in Rockland County and residents of a Suffolk county shelter for battered women.

Feedback from this module is characterized by the overwhelming concern that women — even in difficult life circumstances — have about chemicals in their immediate environments. In every session, questions arose about the range of possible chemical exposures, and what could be done to reduce risk. Facilitators liked the teaching tools we included, but hoped for larger, more colorful versions of the visual aides, as well as other types of "giveaways" to help teach and remind in the home. Facilitators also looked for more background learning material for themselves. Many participants and facilitators were interested in alternatives to strong cleaning chemicals, and many inquired about any link between chemicals in the home and childhood asthma.

• Pieces of the Puzzle: Putting It All Together for Breast Health is aimed at helping rural women to adopt practical breast cancer risk reduction strategies. Pieces of the Puzzle was field tested in Chautauqua, Wyoming, Yates, Herkimer and St. Lawrence counties. Groups included Fire Hall Ladies' Auxiliaries in Chautauqua county and a choral club in Wyoming county, as well as grassroots health promoters, and two shifts at a Kraft's Foods plant in St. Lawrence county.

Pieces of the Puzzle provides the core information on breast cancer risk factors for the Tool Kit. Facilitators were successful in using this module with groups of rural women. Participants liked the craft projects that reinforced the teaching messages, including the 4Es for breast health (eating, exposure, exercise and exams). We have decided to feature this "core" curriculum in all Tool Kit orders; in other words, when any module is ordered, a copy of this core curriculum will be included. Educators can choose to use it for their own background, or to teach it as part of their program.

• Making the Connection: Breast Cancer Risk Reduction in Health Settings includes tools for creative integration of breast cancer risk reduction messages in community health care and breast cancer screening settings, especially in rural areas. Making the Connection was tested in Delaware, Yates, St. Lawrence, Herkimer and Steuben. Groups included health clinic and hospital staff (nurses, nurse practitioners and physician's assistants, and physicians) in Yates, Delaware and Herkimer counties, nursing students in St. Lawrence, and the Steuben County Wellness coalition of health educators and promoters.

Participants were enthusiastic about applying the new content on risk reduction to their work. They shared their own ways of integrating educational messages into these settings, and developed or reinforced community health networks in their regions. Because of the important and often untapped relationship between providing screening services and education about risk reduction at the same time, BCERF hopes to greatly expand initiatives in this area.

• Growing Healthy Girls was presented as a three-part series of workshops for adult women youth leaders working with preadolescent girls, aimed at strengthening leader skills at modeling healthful behaviors for breast cancer risk reduction. The program features a unique approach: asking participants to look at their own attitudes and how they affect the girls in their lives. Participants have the opportunity to practice

activities they can use in influencing girls and addressing body image issues, as well as physical and nutrition activities. This module was tested in Wyoming, Nassau, Erie and Ulster counties. Most field test sessions were held at the CCE offices. Audiences varied widely, from 4H leaders to nutritionists to teachers to parents. One Nassau county group was held at a literacy project office.

Growing Healthy Girls targets youth leaders as important facilitators of breast cancer risk reduction for two groups: themselves and the girls for whom they serve as role models. Participants were enthusiastic about the program's empowerment approach and requested more discussion time and physical activities. Many raised concerns about eating disorders and how to best work with girls on these sensitive issues. Facilitators recommended reformatting the curriculum for maximum flexibility so it could better meet varied program and audience needs. They also suggested providing a resource guide for themselves and participants, and expanding the audience to include parents. The field test confirmed BCERF's concern that many women are less than comfortable leading physical activities and addressing the social-emotional issues that relate to nutrition, but are eager for practical tools in these areas. It also suggests that the Tool Kit's flexible, varied-format approach is the right direction to go, and that the added dimensions of videos, tip sheets and resource tools will be put to good use.

How We Gathered the Information

We developed and utilized four evaluation instruments for each of the five modules. The four instruments, designed for efficiency, effectiveness and thoroughness, provided us a complete, multi-dimensional picture of each event, even without BCERF staff being there.

The Facilitator's Pre-Session Overview ensured that the field tester had thought through various aspects of the program before carrying it out.

The Facilitator's Post-Session Feedback was described to field testers as "the single most important source of information about how well the program works." It assessed a wide range of aspects of the session, including:

- · audience demographics
- specific characteristics of the presentation
- what worked, what didn't and suggestions for improvement
- participant response and questions
- facilitator satisfaction



Marilyn Wyman (left) Cornell Cooperative Extension of Greene County, field testing Talking Around the Table: Chemicals in the Home.

The *Participant Evaluation* quantitatively measured the degree to which participants found the module informative and valuable on a 5-point scale ("Strongly Disagree" to "Strongly Agree"). Eight of the nine quantitative questions had a common "root question" to allow for later comparison across modules. Optional qualitative questions explored motivation to attend and gathered demographics on rural lifestyle and ethnicity.

Participant Feedback questions, offered in either oral or written form, asked for specific input from participants on what worked, what didn't, and how to improve the program.

In addition to these four instruments, a *Materials Evaluation* form was developed specifically for *Pieces of the Puzzle* and *Making the Connection*. It allowed facilitators to evaluate the supporting BCERF materials, such as "4Es" posters.

Where We Go From Here

Final editing, design and production are underway, with completion expected in early 2002, in time for a satellite

conference tentatively scheduled for April. The goal of this satellite conference will be to increase the ability of community educators nationwide to bring up-to-date breast cancer risk reduction programming into their communities. We hope that participants will come away from the satellite conference with new, science-based knowledge, informed and eager to use all or part of the Tool Kit, and with new community connections as a result of coming together to view the conference.

This will be BCERF's first satellite conference since 1997, and it will reflect changes in the technology that have occurred since then. For example, a supporting web site will offer efficient registration, downloadable materials, and communication with presenters and other participants. Please watch for more information on BCERF Tool Kit availability and satellite conference scheduling.

Research Commentary

Thoughts on Recent Findings Regarding Organochlorines and Breast Cancer Risk

Kirsten Moysich, Ph.D.
Assistant Professor
Cancer Prevention, Epidemiology and Biostatistics
Roswell Park Cancer Institute

Results from a recent publication of a combined analysis of five large epidemiological studies indicated that there was no link between blood levels organochlorine compounds, such as DDT and polychlorinated biphenyls (PCBs), and increased risk of breast cancer (Laden, et al., 2001). This publication has led to some strong reactions from the media in which it was stated that there is now convincing evidence for the lack of an association between these chemicals and breast cancer. Some of these media reports also discredited members of the

environmental and breast cancer advocacy community, as well as the scientific community, who are not entirely convinced that chemicals like PCBs and DDT do not play a role in the development of breast cancer.

As an environmental epidemiologist and a co-author of the recent study, I would like to make the following comments regarding these media reactions:

 The number of well-designed epidemiological studies on the role of organochlorines in the development of breast cancer is still relatively small. Unlike laboratory studies, in which scientists have tight control over the research experiments, epidemiological studies are subject to many sources of bias that can influence the results of our studies. Because of the possibility that so many factors other than the exposure of interest could explain the findings in our line of research, studies on a given exposure (e.g., PCB and DDT blood levels) and a disease (e.g., breast cancer) have to be carried out numerous times in different populations, using different research methods. Thus, as epidemiologists we do not consider the first study that demonstrates a link between an exposure and a disease to be the most important, but rather the 20th or 50th study that shows the same association. This is true for studies on diet and cancer, exercise and cardiovascular disease, as well as smoking and reproductive health. For instance, there is still debate over whether or not a diet high in fat is related to greater risk of this cancer even though a large number of epidemiological studies have been published on this issue. It is baffling why the limited number of studies on organochlorines and breast cancer risk should be evaluated differently. Having said this, I do not believe that the current body of evidence points to a role of chemicals such as PCBs and DDT in the development of breast cancer in general, but I am bothered by the labeling of those who might disagree with me as environmental fanatics.

 Although the existing body of evidence appears to suggest that there is no overall association between organochlorine chemicals and breast cancer risk, there may be subgroups of women who are more susceptible to a potentially harmful effect of these chemicals. First, two out of two studies that addressed this research question among African-American women have demonstrated some evidence that, in this ethnic subgroup, higher blood levels of PCBs were related to greater risk of breast cancer (Krieger, et al., 1994; Millikan, et al., 2000). It should be pointed out that in one of these studies (Krieger, et al., 1994), it could not be ruled out that chance was an explanation for the observed increase in risk. Second, two out of two studies that investigated the effect of PCBs on breast cancer risk among women with genetic characteristics that may make them more vulnerable to a possible adverse effect of PCBs on breast cancer risk, have shown that women with high PCB blood levels and this genetic trait are at higher risk of this disease than women with lower PCB levels, without the genetic trait (Moysich, et al., 1999, unpublished data). Although these findings are very interesting and suggestive, it is possible, just like any other epidemiological association, that they were the result of the numerous sources of bias that cannot be avoided in epidemiological studies. However, these initial findings certainly should be further investigated. In contrast to the views of some, I believe that we do not know the full story of the role of organochlorines in the development of breast cancer at this point and do need future studies in these potentially susceptible subgroups of women. Even though these studies are expensive and time consuming, they deserve the same attention and scientific vigor from the scientific community as do studies on exposures associated with less industry and advocacy interests.

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"We Need to Know"

Ad Hoc Discussion Group

"Learning Together"

The Ad Hoc Discussion Group meeting, hosted by Senator Mary Lou Rath and attended by Senator Pat McGee, took place in Buffalo at the Center for Tomorrow on the Amherst campus on June 29, 2001, with approximately 45 participants.

Discussion Forum. This meeting began with the discussion forum, focusing on Western New York, with four presenters. Nancy Smith, co-chair of the City of Buffalo's Pest Management Board spoke about the Board, as well as seven other relevant organizations. Her goal was to "link at least one person with each." Joanne Janicki, Director of the Western New York Breast Resource Center at Roswell Park, discussed the importance to women with breast cancer of all those working on their behalf, and that finding out about and connecting with new programs is an important activity for her. Kirsten Moysich, a cancer epidemiologist at SUNY Buffalo, talked about her interest in learning more about the population sub-group effects of environmental exposures (please see Dr. Moysich's Research Commentary in this newsletter). Finally, Karen Goodkin, of the Breast Cancer Coalition of Rochester and member of the National Breast Cancer Coalition and NYS Breast Cancer Network, spoke about her group's advocacy, education and local research efforts, as well as her group's desire to establish a research consortium on breast cancer in the Greater Finger Lakes area.

PSUR Panel. After an interactive and healthy lunch, there was a panel on the NYS Pesticide Sales and Use Registry, from the perspective of four panelists. Michael Nierenberg represented the NYS DEC out of the Buffalo office. Bill Smith of Cornell's Pesticide Management Education Program contributed information on the technical aspects of building, maintaining, and improving the database. Audrey Thier of Environmental Advocates described the results of working with the data available to date, saying "we can learn a lot from the data as it is," but that to see beyond large trends there is a need to refine it. She would also like to see access for all citizens, listing of the active ingredient, and statutory electronic reporting. David Hahn-Baker, Chair of the City of Buffalo's Pest Management Board, described the "real opportunities for citizen involvement," and the help the information has provided in guiding the city's pest management approach.

Research Presentations. At the suggestion of Senator Marcellino's office, the two complementary presentations by BCERF staff featured at the previous Ad Hoc meeting were updated and repeated for the benefit of the Western New York audience. Barbour Warren gave a talk entitled, "Childhood to First Child's Birth: A Critical Period for Breast Cancer Risk." He provided background in the cancer biology and the biology of breast development to enable the non-scientist to understand. Suzanne Snedeker followed with an introduction to a very current area of research, premature thelarche (breast development), and its possible environmental connection. This information was well-received by this audience as well.

Community Partners. Linda Burton of Cornell Cooperative Extension of Chautauqua County ended the meeting by speaking about her five years as a community partner with BCERF. Recent initiatives to raise breast cancer awareness and promote risk reduction included youth events, where settings such as fashion shows and theatre projects involved girls creatively and in their own settings.

Responding to many inquiries from our stakeholders for information on Genetically Modified Organisms (GMOs), the coming Ad Hoc meeting will highlight this issue. We apologize for the late notice to our *Ribbon* readers.

The next Ad Hoc Discussion Group meeting will take place on Friday, October 5, 2001 in 178 Stocking Hall Cornell University
Ithaca, NY

Ad Hoc Discussion Group meetings are open to any and all stakeholders to come together to discuss issues related to breast cancer and environmental risk factors.



NEW PUBLICATIONS AVAILABLE!!

Single copies available at no cost. For multiple copies please contact BCERF (address below).

EDUCATIONAL TIP SHEETS

Five *Tip Sheets* on practical strategies to reduce the risk of breast cancer from environmental factors have now been developed. These *Tip Sheets* have been written at or below the 7th grade reading level.

- __What Do We Know About Breast Cancer?
 discusses breast cancer risk factors and general,
 practical tips about how to reduce your risk.
- __Eating Well and Staying Active offers risk reduction tips associated with food, alcohol, breastfeeding and physical activity.
- Pesticides in Your Environment addresses various pesticide-related concerns, including tips for accessing information about pesticides in drinking water, schools and workplaces, and how to reduce your exposure at home.
- __Using Home and Garden Products More Safely provides an easy-to-read, step-by-step guide on how to reduce exposure to harmful chemicals in and around your home.
- ___Breast Cancer Resources On... tells you where to get answers to frequently asked questions related to the topic of breast cancer. Resources refer to New York State and beyond.

FACT SHEETS

Revised: (Please replace your old versions)

- __FS #1—Phytoestrogens and the Risk of Breast Cancer (July 2001)
- __FS #2—Pesticides and Breast Cancer Risk, An Evaluation of DDT, DDE (March 2001)

New:

- __FS #40—Hormone Treatments and the Risk of Breast Cancer
- __FS #41—Polycyclic Aromatic Hydrocarbons and Breast Cancer Risk
- __FS #42—A Woman's Body Type and the Risk of Breast Cancer
- FS #43—Breast Cancer in Men

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Ribbon Survey Brings Good Feedback to BCERF

Results compiled by Neil Rotach, BCERF Administrative Assistant

In the last issue of *The Ribbon* we included a one-page, postage-paid readers' survey. We received over 100 responses so far (and would love to hear more!) and would like to share the results with you.

1. Who are you?

- 35 a cancer survivor
- 28 family of a cancer patient
- 32 friend of a cancer patient
- 11 a cancer activist
- 2 journalist
- 35 educator
- 3 student
- 3 policymaker
- 3 CCE educator
- 1 farmer / farm worker
- 22 healthcare provider
- 13 scientist
- 34 homemaker
- 13 environmental activist
- 2 pesticide applicator
- 20 other

2. Why do you want the information in The Ribbon?

- 101 to educate myself
- 74 to educate others
- 1 for school assignments
- 31 to give to a relative/friend
- 12 to aid my research
- 29 to share with a colleague
- 10 other

3. Do you like the symposium-like format (several related articles on a theme)?

- 94 Yes
- 3 No, I would rather see:

varied format, more variety, format does not matter

4. Please rank the last several issues

	<u>1st</u>	<u>2nd</u>	<u>3rd</u>	<u>4th</u>
Pesticide Sales & Use Registry	41	14	14	13
Premature Thelarche	13	23	20	10
STAR Trial/Tamoxifen	45	19	9	6
Mouse Mammary Tumor Virus	11	27	12	20

We received 23 responses for suggestions for themes.

5. Do you prefer print or would you be willing to switch to electronic?

- 79 print
- 25 electronic

Plus, we received many, many helpful comments to the Editor. We thank you!

What's New on the Web www.cfe.cornell.edu/bcerf/

Early in July the BCERF website was awarded the right to display the HON Code logo. This award certifies that the BCERF website provides accurate health information. It also assures our readers that we comply with a set of ethical standards defined by the Health On the Net Foundation (HON). HON describes its mission as "to guide lay persons or non-medical users and medical practitioners to useful and reliable online medical and health information."

New information is everywhere on the BCERF website. We offer readers a new fact sheet on the role

of PAHs in the risk of breast cancer, as well as a companion bibliography. We also have added fact sheets on Hormone Treatments and the Risk of Breast Cancer and a revised version of our fact sheet evaluating DDT and breast cancer risk.

Lots of other projects are in the works. We hope you will visit our web site, read, learn and give us your opinions on how we can continue to improve.

Marie Stewart, BCERF Webmaster

The Ribbon is published by the Cornell Program on Breast Cancer and Environmental Risk Factors in New York State. Comments are welcome; contact the Editor

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