

A Healthy Baby Girl,

a film by Judith Helfand

"History doesn't repeat itself; it rhymes." --Mark Twain

COMMUNITY ACTION GUIDE

This community action guide was created for use with the video A HEALTHY BABY GIRL, with contributions and assistance from the following:

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A HEALTHY BABY GIRL will appear on P.O.V., PBS's showcase for independent For more information or to order films, visit our website at <u>www.wmm.com</u> Women Make Movies 462 Broadway #500 New York, NY 10013 Phone: (212) 925-0606 Fax: (212) 925-2052 orders@wmm.com



nonfiction film, on Tuesday, June 17, 1997 at 10 p.m. (check local listings)

TABLE OF CONTENTS

A HEALTHY BABY GIRL by Judith Helfand......2

RESOURCES......16

A HEALTHY BABY GIRL By Judith Helfand

Toxic exposure affects the most private parts of our lives. It forces us to give language to things that we otherwise might not talk about in public - body parts, intimate relationships, the future we want to take for granted.

I was twenty-five when I was diagnosed with DES-related cervical cancer; two weeks later, I had to undergo a radical hysterectomy. I went home to my parents in suburban Long Island, to recuperate in the same room where they had brought me home as a newborn. I lay there, overwhelmed, wondering how this drug had so insidiously worked its way into my life. My bed was in the exact same place where my crib had been. That very stability - the same room in the same house - made the abstractions of



"toxic exposure" and "corporate power" into something real and immediate. You get hurt at home, and relationships you hold most sacred are the ones at greatest risk.

A HEALTHY BABY GIRL opens to the melody of a traditional Yiddish lullaby, "Sleep, Sleep, Sleep." The lyrics tell a story of a mother comforting her baby: "Papa will come to the village, he'll bring an apple to heal your head, nuts to heal your feet, soup to heal your tummy" - wholesome foods to heal any ailment. The song speaks to what has been lost - my parent's ability to protect me with simple nurture, my own ability to bear children. But the Eastern European Jewish klemzer music in the film is also used to reclaim what DES and toxic exposure have threatened family, tradition, and continuity.

Because of DES, my parents and I had to find new ways to care for each other. Filming for five years wouldn't have been their first choice, but they did it for me. In the process, they taught me what parenting really means. Perhaps most important, they showed me that we can't lose our sense of humor, even in the face of tragedy. Because if we had lost our ability to laugh, we really would have lost everything.

So I'm inviting you to laugh with us. I hope that it will serve as a reminder that our collective humanity is more powerful than toxic and environmental threats that face us.

REFLECTIONS ON "A HEALTHY BABY GIRL" By Philip J. Landrigan, M.D. Chair, Department of Community Medicine Professor of Environmental Medicine and Pediatrics The Mount Sinai Medical Center, New York City Co-Author, Raising Children Toxic Free

As a physician who has made children's health my specialty, and their future my priority, I consider A HEALTHY BABY GIRL a remarkable video.

In A HEALTHY BABY GIRL, Judith Helfand tells the story of her diagnosis at age 25 with clear-cell adenocarcinoma of the cervix, a rare tumor now known to be caused by exposure to the synthetic chemical hormone diethylstilbestrol, DES.



Judith's exposure to DES took place when she was still in her mother's womb.

Judith's story teaches us many lessons. First, it reminds us in the most vivid terms that the youngest members of the human family - embryos, fetuses, infants, and children are the most vulnerable among us to chemical toxins in the environment. Particularly in the earliest stages of human development, there exist windows of extraordinary vulnerability when exposure to chemicals such as DES can cause devastating effects whose consequences last a lifetime.

The DES story makes us all aware that there exist intergenerational toxins, synthetic chemicals which wreak havoc on our endocrine systems. When DES is given to adults the immediate effects are relatively mild. But when a fetus is exposed to DES, as happened in Judith's case, the effects can be catastrophic. The damage to developing cells that is caused by DES becomes evident only two, three, or four decades after exposure.

DES does not exist in isolation but is part of a much larger story in American society of widespread exposure to inadequately tested synthetic chemicals. In the years since World War II, more that 75,000 new chemical compounds have been developed, and are being used in drugs, pesticides, food additives, cosmetics, and industrial chemicals. Fewer than half of these chemicals have been tested for their potential toxicity to humans, and fewer still have been tested for their potential to cause toxic effects in fetuses and the very young. Through our heedless behavior, our society is by default conducting a massive clinical toxicological trial. In this trial, our children and our children's children are the experimental subjects.

And we know some of these chemicals. The DDT that was sprayed in our yards, chlorinated solvents used on the shop floor, the chlorine bleach in our paper, the dioxin byproducts of PVC plastic burned in our hospital incinerators. Like DES, some of these chemicals are hormones, with the potential to disrupt our endocrine systems - increased risk of spontaneous abortion, cancer, reproductive and developmental disorders, effects on our



neurological and immune systems. Our exposure is cumulative over our entire lifetimes, as our bodies store these toxins in our fatty tissues. Those who suffer most severely the effects of this environmental degradation are the most vulnerable - developing fetuses and children.

Three points are important to note:

- The carcinogenicity of DES was, in fact, recognized in animal's years before any cases of clear cell cancer were diagnosed in young women. This information was, however, not heeded by the pharmaceutical industry in marketing the drug.
- Long after DES had been found to have no value in preventing miscarriages, and after it was contraindicated for use during pregnancy in this country, the pharmaceutical industry continued to market DES overseas.
- Likewise, the carcinogenicity of dioxin, DDT and other toxins has been knows for years, yet the chemical industry continues to produce these environmental toxins in the U.S. and overseas.

A final lesson that we can take from Judith's story is the importance of taking action and of not falling into despair. Judith's life is a lesson about the dangers of putting untested chemical agents into people's bodies, about the dangers of heedless chemical pollution of the planet, about the dangers of heedlessly burning toxic waste, about the dangers of letting industry operate without oversight and accountability. Her story is a powerful stimulus to action, a wake-up call to bring the scientific and political abstractions of "toxic exposure" literally home to us.

Most important to remember is that we are not helpless the pages that follow show some of the key questions you can ask in your daily life, and point to resources you can use to protect the health of future generations.

USING "A HEALTHY BABY GIRL" To Build Community Alliances By Judith Helfand and Pamela Calvert



Communities are divided by class, race, and power. But toxic exposure does not respect geographic or social boundaries. The struggles faced by a DES-exposed family in a Long Island suburb are intimately related to those of agricultural workers using pesticides, Agent Orangeexposed Vietnam veterans, and nerve gas incinerator "downwinders" in Utah. What links them is a single group of devastation across space and time.

Often the very groups that are fighting toxic issues are known to the public only in the heat of the battle. Their image is commonly presented by the media as confrontational and single issue-based. Though a position on the frontlines is critical, groups can also get trapped by stereotyping, isolated from the very people they're advocating for. Communities facing toxic exposure can't afford to be divided in these ways.

A film as personal as A HEALTHY BABY GIRL gets people together and talking in a non-threatening atmosphere. The story of a middle-class suburban Jewish family openly dealing with the impact of DES-related cancer translates the abstract threat of toxic exposure into something that can happen to anyone. An emotional and empathetic response from a roomful of strangers stimulates conversations that challenge long-held social attitudes about who is sage and who is vulnerable. This is an opportunity to bring together people who might never meet each other -a hazardous materials trainer from a plastics factory, a suburban DES mother, an activist from a working-class community dealing with cancer clustersgenerating "unlikely alliances" across class lines and opening the opportunity for collective action.

How can A HEALTHY BABY GIRL foster these alliances, and what effect can they have?

- In Northhampton, Massachusetts, our screening at that town's film festival generated a half-page feature story in the local newspaper linking DES to Western MassCOSH's work on toxic exposure and reproductive health hazards from pesticides and manufacturing. The community gained a new perspective on a workplace health and safety organization as fighting public health battles on their behalf.



- At the Sundance Film Festival, in Utah, we invited activists into our festival screenings who are working against the nearby dioxin-emitting nerve gas incinerators. This led to local news reports on the health connections between DES and dioxin, as well as a major story in the daily newspaper, focusing on the antiincinerator work of the West Desert Healthy Environment Alliance. As a result, the Utah PBS affiliate committed to produce a civic roundtable at the time of A HEALTHY BABY Girl's broadcast-inviting the coalition on environmental and health activists we had identified.

WHAT IS THE HEALTHY BABY GIRL STORY IN YOUR COMMUNITY?

With this community action guide, you can plan a screening of A HEALTHY BABY GIRL that brings your community together to deal with the threat of endocrine-disrupting chemicals. We recognize that people find these issues frightening and overwhelming - which can lead to paralysis or cynicism-so this guide provides concrete resources and actions. It is possible to feel vulnerable and powerful at the same time, and that is the perfect moment to organize. You can start by taking these steps:

- What is the "Healthy Baby Girl" story in your community? It might be something that you've been working on for a long time. Or there might be more than one story. It might be hospital incineration, or pesticides, or a neighborhood cancer cluster: you can use the discussion questions in the next section as a checklist.
- Who are the people or organizations working on the issue, really putting themselves on the line? Are they working in isolation? In what context does the community know them? How would coalition-based support advance their work and lead to greater health for the community as a whole?
- Beyond the groups working directly on the specific toxic issues you have identified, where are other potential allies? DES-exposed people, cancer survivors, and secular and faith-based advocates for family health, the environment, and workplace health and safety all have a stake in your community focusing on endocrine-disrupting



toxins. However, they may have no experience in working together. Identifying and enlisting a broad range of sponsors for a screening of A HEALTHY BABY GIRL-not just the "usual suspects"-will bring diverse constituencies into the room, making "unlikely alliances" and collective action possible. You can use the resource section at the end of this guide for leads: call the national organizations listed for local affiliate contacts, or find local counterparts.

- The press can play a powerful role in your strategy. Make the connection between A HEALTHY BABY GIRL and your community's story, using the screening and the phot-op of your unlikely allies as the news "hook" which makes the story timely and compelling. Be creative when approaching the press: you might get a positive response from arts, science, health, "living"section, religion, or metro reporters, depending on the specifics of your situation.
- Use our website (<u>http://www.itvs,org/babyg</u>): we will have information there about what other people around the country are doing, and ask that you share your ideas, successes, and challenges as well. We would love to hear about your plans and the links you're making in your community. We will be able to talk about your work in national press interviews, gaining more visibility for the national HEALTHY BABY GIRL project as a whole and your community in particular.
- Once you're planning the screening, remember that the size jof the gathering is not the primary goal. Your event can be a success whether there are 10, 40 or 80 people. These forums are about talking together and building new alliances.
- Use this guide liberally in structuring your event. Before the screening, you can introduce this film by reading the filmmaker's statement. When the lights come up, people will have a strong emotional response to the film. This is where people make the empathetic connections that make all the following work possible, so it's important to encourage that personal response before moving on to discussions of strategy. The conversation will naturally flow into "What do we do now?" They will



be looking for something immediate, concrete, and local. In addition to the resources and campaigns you bring to the screening, you can use the discussion questions as a jumping off point.

- Please make sure to document your discussion following the screening. You might want to videotape your discussions, use audio, or simply take notes and write up a summary. Be sure to take a group photo! Whatever method you choose, please share the results with us afterwards on the website.

"FIND THE RHYME": Discussion Questions

"History doesn't repeat itself; it rhymes." -Mark Twain

The connections between DES and toxins like incinerator emissions and pesticides might not be apparent immediately. We hope that the above material makes that link clear: we face the same trans-generational health risks from our exposure to all endocrine-disrupting chemicals. The following questions are intended to help you and your neighbors find the rhyme, the "Healthy Baby Girl" story in your home, your workplace, and your community: "See the Resource List for more information on organizations and publications cited."

"How can I find out whether I was exposed to DES, and the actions I need to take if so?"

Many people do not know that they were exposed to DES. Mothers may not have known they were taking DES or remember the kinds of medications they were given when they were pregnant; some prescription vitamins included DES. "Any" woman who received medication between 1938 and 1971, and the child she was carrying, may be DES exposed. Try to get the medical records from your (or your mother's) pregnancy from either the attending physician, the medical records department of the hospital where the birth took place, or the pharmacy where the prescriptions were filled.

All DES daughters need regular screening exams for CCA throughout their lives; in addition, they need special care



beginning in the first weeks of pregnancy, even if they have already had children. DES sons should practice testicular self-examinations regularly because of increased risk for non-cancerous cysts as well as for cancer. DES mothers are advised to pay particular attention to their breast care because they may be at increased risk for breast cancer. >"For more information: DES Action; DES Cancer Network

"What medications are my family and I taking, who manufactures them, how have they been tested, and what are their potential side effects?"

The best place to start informing yourself is by consulting two sources, the "Physicians Desk Reference" and "Worst Pills, Best Pills." Be sure to ask for "med guides" from your physician and/or pharmacist for more detailed information on your prescriptions, including contraindications and possible side effects. >"For more information:" Worst Pills, Best Pills; Physicians desk Reference; "Center for Medical Consumers"

"What toxins has my food been exposed to before it reaches my table? What are the effects of those toxins? What are the alternatives?"

Dioxin is in all our bodies; the U.S. EPA estimates that 90% of that dioxin comes from our food. For many people, more than three quarters of that dioxin comes from beef, dairy products and seafood. Dioxin accumulates in fat, working its way up the food chain. People with high levels of dioxin may experience infertility, higher rates of endometriosis in women, and immune system damage.

Even though few dairy and beef farms are in the immediate vicinity of dioxin-emitting incinerators, airborne dioxin from incinerators and cement kilns can travel up to 1,000 miles, falling on grazing land, where it sticks to grass or hay eaten by cattle.

Coastal fish and shellfish have higher levels of dioxin due to pollution of coastal sediments. Low-income communities are often more likely to rely on subsistence fishing to provide food, and so are more likely to be affected. These

STUDY GUIDE Women Make Movies

communities are also most often the locations for incinerators.

We can cut down our dioxin exposure by reducing consumption of fish, poultry, meat and dairy products, but eliminating animal fats from our diets will not stop the continued production of dioxins, nor will it protect those who live near industrial sites and dumps contaminated by dioxins that they absorb directly through their water and air. Actions to reduce dioxin contamination of the U.S. food supply include phasing out chlorine use in manufacturing, and switching from waste incineration to recycling.

Even organic vegetables are susceptible to contamination by airborne pesticide "drift."

No one can live in a nontoxic environment if their community is using pesticides; aerial causes five times greater loss of pesticides to drift than ground spraying. Even under ideal conditions only about 50% of aerial spray reaches the target, with the rest going wherever the wind carries it. The only way to stop the problem of drift is to change broadcast spraying methods, and to explore nontoxic methods for community pest control.

>For more information: National Coalition Against the Misuse of Pesticides; Mothers and Others for a Livable Planet; Citizens Clearinghouse for Hazardous Waste

"Where is the nearest incinerator to my home? What is being burned there, and what are the risks from emissions?"

Incinerators have been dubbed "landfills in the sky," because they transform toxic waste into gaseous emissions which are dispersed into the air over land and into the water regardless of whether they are burning hazardous, medical, military, municipal, or Superfund waste. Newer, safer alternatives to incineration currently exist, but billions of dollars in contracts and outdated EPA policies perpetuate incineration across the country.

There are no epidemiological studies to validate the EPA's position that incinerators pose no risk to human health or the environment. Such assurances are based upon "health



risk assessments," written by consultants who work for the incinerator industry.

About 85% of medical waste is incinerated; in all, medical waste accounts for 10% of all incineration in the U.S. On average, less than 5% of medical waste needs to be incinerated. Most other waste can be processed through less aggressive methods, which have not been associated with dioxin.

As a first step, call your state EPA to find out about incinerators in your area, but bear in mind that they will not have a complete inventory of sites. You can also call hospitals in your area and ask if they burn their medical waste on-site. If so, you can organize a local Health Care Without Harm initiative, and "adopt a hospital."

>For more information: Taking Action to Stop Dioxin Exposure; National Coalition Against Incineration; Health Care Without Harm/Citizens Clearinghouse for Hazardous Waste

How can I clean up the toxins in my workplace, and how can I find out what non-toxin alternatives might exist?

Workers are on the 'front-line' of chemical exposure, often exposed to high concentrations of toxins. The effects may take time to show, or may appear in the workers' children. In some industries, such as electronics, people of color and women of child-bearing age are those most heavily exposed to the toxic chemicals.

If your occupation is covered by the Occupational Safety and Health Administration (OSHA), you have the rifht to annual training in chemical hazards, to have the hazardous materials you work with properly labled, and to know about the hazardous substances you are being exposed to through "material safety data sheets" (which are written by the producers and / or the users of the chemicals). In addition, most states have their own right-to know acts, which give all workers the above rights regardless of their federal OSHA status. If you are in a union, you have the added option of writing specific health and safety language into your contract.



If you have questions or concerns about the risks you are running at work, you should contact your state COSH (Committee for Occupational Safety and Health) group—if there isn't one in your state, call the one nearest to you. Information on alternative substances varies from industry to industry, but a good place to begin is the Toxic Use Reduction Institute.

>For more information: NYCOSH; Toxic Use Redustion Institute

How can I balance eliminating toxic industries form my community with the risk of the workers losing their family's livelihoods-maybe even my own family's livelihood?

Justice for the ecosystem and justice for working people are iseparable-just as pollution respects no national boundaries, neither does the stateless multinational corporation. The rules of the game allow corporations to flee to low wage and low regulatory area. Just by threatening to leave, these giants gain leverage over North American public policy; to add insult to injury, this also allows corporate interesets to pit dislocated workers and environmental advocates against each other. By preying on job fear, industry-backed groups can use working people as cannon fodder in their attack on environmental regulations.

Any hope of a sustainable future has to rely on getting working people from here to there with their lives and livelihoods intact. What is needed is a "Just Transitions" policy to provide full income for working people and support for communities negatively impacted by bans and phase-outs of hazardous substances.

>For more information: Public Health Institute

Sources-See Resource List for Organizations: DES: The Basic Booklet, National Institute of Health 1995 (DES Action) "Our Barbies, Ourselves: The End of Innocence in the Age of Dioxin," The Green Guide#23, 4/18/96 (Mothers and Others) Taking Action to Stop Dioxin Exposure (Citizens Clearinghouse for Hazardous Waste) "Where There is Spray, There is Drift," The Green Guide #11, 6/1/95 (Mothers and Others)



A BRIEF HISTORY OF DES

The history of DES is a paradigm for what we confront today in terms of toxic exposure and how it affects our lives, especially since the disease and suffering caused by DES and other hormone-disrupting chemicals were and are wholly preventable.

1938: Diethylstilbestrol (DES) created.

DES was the first synthetic estrogen ever synthesized; it was cheap to produce, more potent than natural estrogen, and could be taken orally. In the rush to make and market DES, Eli Lllly became one of the drug's major manufacturers. In America alone there were 267 drug companies that made and sdistributed DES and other similar synthetic estrogens, because it was unpatented and easily produced.

From the start, studies showed that DES promoted cancer in lab animals:

1938: Mice exposed to DES developed breast cancer. 1939: A rat exposed to DES developed mammary carcinoma. 1939-1940: Mice Exposed to DES were born with malformed reproductive organs.

- 1941: DES approved for medical use in human beings. Despite the evidence from animal studies, the FDA approved the use of DES to treat vaginitis, gonorrhea, menopausal symptom, and to suppress lactation-but not for use during pregnancy. Once FDA approval was granted for these limited uses, however, there was nothing to prevent drug salesmen from suggesting, and physicians from prescribing, DES for any other medical condition-menstrual problems, morning sickness, infertility, and many other applications.
- 1947: DES approved for use during pregnancy. At the prodding of the drug companies reacting to market demand, the FDA approved the use of DES during pregnancy. No controlled studies had been conducted by the drug companies to determine the effectiveness or safety of DES for juse during pregnancy.



DES was intially recommended for women with conditions such as diabetes, or those at high risk for miscarriages; however, it was soon widely prescribed for women with no apparent problems at all, and was the active ingredient in some "vitamin" tablets given to healthy pregnant women.

1952: Some scientists publicly questioned the efficacy of DES.

The largest and best publicized controlled DES study at the University of Chicago in 1953 showed it had "no beneficial effect whatsoever" in preventing miscarriage, and in fact, DES brought about higher rates of premature birth and infant mortality. These findings were supported by several other studies done in the 1950's.

1959: DES banned in chicken and lambs.

DES was used widely in agriculture beginning in 1941 to fatten livestock and chickens. Exposed male agricultural workers suffered sterility and breast growth as a consequence. When high DES levels in poultry produced similar symptoms in consumers as well, the FDA banned the use of DES in chicken and lambs in 1959.

1960s: Six of the seven leading obstetrics textbooks stated that DES did not prevent miscarriage in any group of patients.

DES was still being prescribed to pregnant women and touted as a "wonder drug."

1970: Unprecedented appearance of rare cancer in young women. A rare vaginal cancer, CCA (clear cell adenocarcinom), began to show up in unprecedented numbers in young women. There were eight such cases at Massachusetts General Hospital in Boston alone. One of the mothers raised the question whether her daughter's cancer might be connected to DES exposure in utero.

1971: Doctors confirmed the link between CCA and DES. The findings of the Boston doctors were published in the New England Journal of Medicine, April 22, 1971. Only



then did the FDA issue an alert advising against the use of DES during pregnancy. Even so, some physicians in the US continued to prescribe it for a few years to pregnant women despite the FDA alert.

Companies continue to sell DES overseas even after 1971; while it was no longer used in most western European nations by the late 1970's, DES continued to be sold through the 1980's in much of the rest of the world.

- 1975: DES Action formed. See Resource List
- 1979: DES banned in animal feed Cattle breeders fought regulations of DES in feed until the Department of agriculture finally banned it in 1979, but there were reports of its covert use throughout the early 1980s.
- 1982: DES Cancer Network formed. See Resource List
- 1992: National Institute of Health (NIH) convened the first ever meeting on the long-term effects of DES.
- 1992: DES bill passed.

Congress unanimously passed the DES Education and Research Amendment (chief sponsors Rep. Louise Slaughter [D-NY] and Sen. Tom Harkin [D-IA], providing funding to the National Institute of Health for research on mothers and children, and for a public and physician education campaign.

1993: Long-term DES research expanded. The NIH began new studies on the long term medical effects of DES, such as breast cancer in the daughters, immune system disorders, and reproductive problems in the sons, as well as the long term health effects of the various treatments for CCA.

TODAY

Since 1971, the devastating effects of DES exposure discovered include:



Structural damages in reproductive organs of DES sons and daughters;

High risk pregnancies and miscarriages for DES daughters;

Increased risk for infertility in sons and daughters; Increased risk of breast cancer in DES mothers; Immune system impairment in some mothers and children exposed to DES

There are an estimated 10 million DES mothers and children in the United States today. Current statistics indicate that one in a thousand DES-exposed daughters will get CCA, the clear cell cancer originally linked to DES in 1971. Effects on the third generation-DES grandchildren-are as yet unknown. To this day, none of the 267 pharmaceutical companies who produced and distributed DES has accepted any responsibility for the DES tragedy, and all continue to claim that DES causes no health problems. Eli Lilly, the largest manufacturer, has been a defendant in the majority of lawsuits brought by victims of DES related cancer, infertility, and birth defects.

DES is still sold in many developing countries for a variety of reasons (suppression of lactation, menopausal symptoms, etc.) there have been reports of the continued use of DES as an anti-miscarriage drug in China, Mexico and parts of Africa. Today, there is no definitive estimate of how many million mothers and children have been exposed to DES worldwide.

After DES was no longer marketed for use in pregnancy in the U.S., drug companies promoted it for other usesparticularly in hormone replacement therapy and as a "morning after" abortion pill. Although both of these uses have now been discontinued, DES is now sometimes prescribed in the U.S. to patients with breast and prostate cancer, no medical concerns have been raised about its side effects in treating these conditions.

To this day, no studies have been done on the long term effects of DES exposure on agricultural workers, not is the impact of exposure on pharmaceutical company employees known.



Synthetic hormones like DES are known as endocrine disruptors, wreaking havoc on the hormonal system. These chemicals are called "hand me down poisons" by the authors of the book Our Stolen Future (see Resource List), in that their toxic effects are not only experienced by those who are directly exposed, but also show up in descendants as birth defects, cancer, or infertility. Such chemicals are in pervasive use today in pharmaceuticals, pesticides, and manufacturing; the resources and facilities simply do not exist to detect, test, and regulate more than a tiny fraction. Dioxin, DDT, Agent Orange, PCB's- all with hormone like effect-are chemical siblings of DES with similar potential effects on the human body. The very nature of their toxicity- to our reproductive abilitiesbears a potent threat for our future.

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STUDY GUIDE Women Make Movies

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Breast Cancer Action 55 New Montogomery #624, San Francisco CA 94105 Phone: (415) 243-9301 Fax: (415) 243-3996 E-mail: <u>bcaction@hooked.net</u> URL: <u>http://www.med.stanford.edu/bca</u>

Breast Cancer Action was founded by a group of women seeking substantive information about the causes and treatment of breast cancer. fed up with unresponsive agencies and inadequate, superficial answers to their questions, they decided to find their own information about their disease and to make that information available to others. Through education and advocacy, they are working to make eradication of breast cancer a national priority.



They promote research into the causes, prevention, treatment, and cure of breast cancer, and work to empower women and men to participate fully in decisions relating to this disease.

Center for Medical Consumers 237 Thompson St, New York NY 10012-1090 Phone: (212) 674-7106 Fax: (212) 674-7100 www.medicalconsumers.org

Center for Medical Consumers is a non-profit organization dedicated to helping people make informed choices about medical care. Their New York City office has a library designed specifically for the lay public containing subject files, books, and periodicals on both mainstream and alternative treatments. They offer information ranging from options for breast cancer treatment, to drug side effects, to doctors' credentials. They also offer a newsletter, "Health Facts" that brings this information into people's mailboxes every month.

Children's Health Environmental Coalition (CHEC) PO Box 846, Malibu CA 90265 Phone: (310) 573-9608 Fax: (310) 573-9688 URL: http://www.checnet.org

CHEC is a national non-partisan grassroots organization dedicated to protecting our children from the threat of environmental toxins. CHEC works to link policy makers, the scientific community, parents and grassroots groups through an information clearinghouse, an interactive website, meetings, symposia, and the promotion of legislation.

Citizens Clearinghouse on Hazardous Waste (CCHW) PO Box 6906, Falls Church VA 22040 Phone: (703) 237-CCHW E-mail: <u>cchw@essential.org</u>

CCHW has worked with over 8,000 community based groups nationwide on toxic hazards, helping communities to understand, often for the first time, why their families are sick, or what type of cleanup is needed. CCHW provides organizing assistance and leadership training, and publishes self-help guides and fact packs to fill the needs of grassroots groups. CCHW publishes "Everyone's Backyard"



a quarterly magazine that features news on what's happening in the grassroots movement for environmental justice; and "Environmental Health Monthly" a journal reprinting medical and scientific articles on health and chemical exposures. CCHW is coordinating the "Health Care Without Harm" campaign, whose goal is to transform the health care industry so it is no longer a source of environmental harm.

Coalition on the Environment and Jewish Life 443 Park Avenue S., 11th Fl., New York NY 10016 Phone: (212) 684-6950 Fax: (212) 686-1353

COEJL is coordinated by the National Jewish Community Relations Advisory Council (13 national organizations and 117 community relations councils) the Jewish Theological Seminary, and the Religious Action Center of reform Judaism. Annual campaigns reach thousands of communal bodies integrating environmental themes into traditional religious observances.

DES Action USA 1615 Broadway #510, Oakland CA 94612 Phone: (510) 465-4011 or (800) DES-9288 E-mail: desact@well.com URL: http://www.desaction.org

A national non-profit organization representing an estimated 10 million mothers and children exposed to DES. The organization provides education and support to those exposed to DES so that individuals discover if they are exposed, and to educate medical professionals so they can provide knowledgeable services to DES exposed people. In the U.S., DES Action volunteers lead 24 affiliate groups nationwide-both state affiliates, and the DES Sons Network and the DES Third Generation Network. They are politically active in garnering support and funds for DES research. There are also DES action affiliates in Britain, Canada, throughout Europe, and Australia.

DES Cancer Network 514 10th Street NW, Washington DC 20004 Phone: (800) DES-NET4 or (202) 628-6330 Fax: (202) 628-6217 E-mail: <u>desnetwrk@aol.com</u> www.descancer.org



It is estimated that as many as 1 out of every 20 people in the United States is a DES exposed mother, daughter, or son. Half of those exposed are unaware of their risk. The DES Cancer Network works to educate and increase public awareness of DES related illness. They focus particularly on the special needs of women who have had clear cell adenocarcinoma of the vagina or cervix- a cancer linked to exposure to DES before birth. In addition to advocating research, they provide an international support system that gives members access to one another and to information about clear cell cancer.

Environmental Research Foundation PO Box 5036, Annapolis MD 21403-7036 Phone: (410) 263-1584 Fax: (410) 263-8944 E-mail: erf@igc.apc.org www.rachel.org

ERF publishes "Rachel's Environment and Health Weekly" a newsletter that covers a wide range of issues for the public and activists concerned with toxic exposure and environmental justice. ERF can also provide information and fact packs for communities and activists on a wide variety of environmental and health issues.

Evangelical Environmental Network 10 E.Lancaster Avenue, Wynnewood PA 19096 Phone: (610) 645-9392 Fax:(610) 649-8090 www.creationcare.org

The Evangelical Environmental Network (EEN) was initiated by World Vision and Evangelicals United for Social Action in 1993 as a part of a growing movement among evangelical Christians to develop a biblical response to the disregard of God's creation. It was formed in response to recognition that environmental problems are at their roots spiritual problems, and require a response grounded in "faith". The EEN has sent out more than 30,000 resource kits to evangelical churches across the U.S., collaborates on the publication of a quarterly magazine, "Green Cross" and organizes conferences for pastors and leaders of Christian organizations.

Greenpeace 1436 U Street NW, Washington DC 20009

STUDY GUIDE Women Make Movies

Phone: (202) 319-2433 Fax: (202) 462-4507 www.greenpeace.org

Greenpeace is an international environmental organization committed to creating a green and peaceful planet using non-violent direct action to confront polluters. Greenpeace works to protect the world's oceans and forests and to eliminate the health and environmental threats posed by fossil fuels, nuclear power, nuclear weapons, and toxic pollution. Greenpeace's toxic campaign is working across the globe for a phase out of polyvinyl chloride (PVC) plastic, since the lifecycle of this poison plastic-from production and use to disposal-is linked with the generation of dioxin, the most toxic synthetic chemical known to mankind. Greenpeace works to prevent disease and make the world a safer place for our children by eliminating dioxin and other toxic chemicals that threaten public health.

Mothers and Others for a Livable Planet 40 West 20th Street, New York NY 10011-4211 Phone: (212) 242-0010 or (888) ECO-INFO Fax: (212) 242-0545 E-mail: <u>mothers@igc.apc.org</u> <u>greenguide@igc.apc.org</u> URL: http://www.mothers.org/mothers

Mothers and Others is a national consumer education and advocacy organization working to promote consumer choices which are safe and ecologically sustainable for current and future generations. They work to educate consumers regarding the dangers of pesticides on food, and to encourage sustainable choices in the marketplace.

National Coalition Against Incineration RR4 Box 53A, Jersey Shore PA 17740 Phone: (717) 398-7383 Fax: (717) 398-2014 E-mail: Vsmedley@oak.kcsd.kl2.pa.us

The National Coalition Against Incineration is composed of grassroots citizen groups from around the United States who oppose the incineration of hazardous wastes. They are working to translate regional fights against local incinerators into a nationwide campaign to stop the construction and operation of dioxin-emitting incinerators. They have called for an investigation into the relationship between the EPA and their contractors, and have challenged



the EPA to acknowledge its own findings regarding dioxin exposure, and, based on those findings, to permanently suspend all Superfund and hazardous waste incinerator operations in the U. S.

National Coalition Against the Misuse of Pesticides 701 E Street SE #200, Washington DC 20003 Phone: (202) 543-5450 Fax: (202) 543-4791 www.beyondpesticides.org

The National Coalition Against the Misuse of Pesticides represents a broad coalition of health, environmental, labor, farm, consumer and church groups, as well as concerned individuals, who share common concerns about the potential hazards associated with pesticides. They advocate for policies that better protect the public from dangerous pesticide exposure and work to focus public attention on the dangers of pesticide poisoning. They also provide information on alternative pest management strategies, including least toxic methods of controlling specific pests in and around the home as well as in public facilities and in agriculture.

National Religious Partnership for the Environment 1047 Amsterdam Avenue, New York NY 10025 Phone: (212) 316-7441

URL: http://www.nrpe.org

National Religious Partnership for the Environment is a federation of major American faith communities-the U.S. Catholic Conference, the Coalition on the Environment and Jewish Life, the National Council of Churches of Christ, and the Evangelical Environmental Network-working to integrate commitment to global sustainability and environmental justice permanently into religious life. They provide information for organizing religious groups on environmental issues and for using resources unique to the religious community to encourage initiatives rising above self interest toward the common good.

National Women's Health Network 514 10th Street NW #400, Washington DC 20004 Phone: (202) 347-1140 Fax: (202) 347-1168 Clearinghouse: (202) 628-7814



The National Women's Health Network is an advocacy organization giving women a greater voice in the health care system in the United States. They are the only such membership organization, directing people and policy toward solid health care. The Network educate people about health care to make them better informed health consumers, and monitors health-related legislation to protect women's health rights. The Clearinghouse staff gives information over the phone and through the mail.

New York Committee for Occupational Safety and Health (NYCOSH) 275 6th Avenue, New York NY 10001 Phone: (212) 627-3900 www.nycosh.org

NYCOSH is a non-profit coalition of 200 local unions and more than 400 individual workers, physicians, lawyers, and other health and safety activists-all dedicated to the right of every worker to a safe and healthy job. Part of a national network of 25 union-based safety and health organizations, NYCOSH helps workers learn how to protect themselves by teaching them about the hazards in their workplace, and by showing them ways to control and eliminate the dangers. NYCOSH also helps unions develop strategies for confronting management so workers don't have to choose between their jobs and health.

Physicians for Social Responsibility 1101 14th Street NW #700, Washington DC 20005 Phone: (202) 898-0151 Fax: (202) 898-0172 www.psr.org

With more than 20,000 U.S. members and over 90 local chapters, PSR works to protect people from environmental health hazards and to shift government spending priorities away from wasteful military expenditures and toward investments in public health and the environment. PSR's priorities include educating medical professionals about environmental health hazards, and advocating for environmental clean-up laws that mandate public health protection, a national program to assess the health hazards of abandoned hazardous-waste sites, and policies forcing the U.S. military to comply with federal environmental laws and regulations.



Public Health Institute 835 Broadway #2014, New York, NY 10003 Phone: (212) 674-3322 Fax: (212) 353-1203 www.phi.org

The Public Health Institute addresses the growing jobsversus-environment conflict by building connections between unions and various elements of the environmental and public health communities. They work to demonstrate that the same groups who profit from weak toxics regulation also profit from the destruction of stable jobs. By bringing both concerns to the table in this context, the Public Health Institute facilitates the development of fair approaches to phasing out the use of toxics, and increases the strength of both movements by forging alliances between them.

Public Interest Research Group (US-PIRG) 218 D Street SE, Washington DC 20003 Phone: (202) 546-9707 Fax: (202) 546-2461 www.pirg.org

US-PIRG is a non-profit, non-partisan organization dedicated to serving as a watchdog for the nation's citizens and the environment. They work on a wide range of issues-from consumer safety to alternative energy sourcesall with the central goal of protecting the public interest. US-PIRG combines the expertise of professionals with the power of citizens to fight wherever their campaigns take them: from Congress to the courts, to corporate board rooms, and to government agencies and the news media.

RESOLVE, Inc. 1310 Broadway #6M, Somerville MA 02144-1731 Phone: (617) 623-1156 Fax: (616) 623-0252 www.resolve.org

RESOLVE is a national non-profit organization that, for more than 20 years, has assisted people in resolving their infertility by providing information, support, and advocacy. RESOLVE is headed by a volunteer board which includes individuals who have experienced medical concers regarding infertility, and who have adopted children. RESOLVE advocates on the national and local level for



comprehensive insurance coverage for infertility treatment and other family-building issues of concern.

Right-to-Know Network (RTK NET) Phone: (202) 234-8494 Fax: (202) 234-8584 Modem Access: (202) 234-8570 <u>http://www.rtk.net</u> Telnet: rtk.net <u>gopher.rtk.net</u> <u>ftp.rtk.net</u> email: admin@rtk.net

RTK NET is an online computer network providing free access to the latest national right-to-know databases. You can identify valuable data about environmental and housing conditions in your community, as well as information about campaign contributions to your Congressperson. RTK NET also provides users with e-mail, online conferences, and an electronic library of information.

Toxic Use Reduction Institute (TURI) 1 University Avenue, Lowell MA 01854-2866 Phone: (508) 934-3275 Fax: (508) 934-3050 URL: http://www.turi.org

TURI publishes a variety of technical and policy reports on toxics use reduction and pollution prevention, and houses the Technology Transfer Center, a research library and information clearinghouse. The Center responds to information requests by searching its library collection and computerized databases, a service accessible by phone, mail or fax. the Center has a collection of more than 15,000 books, conference proceedings and technical papers and periodicals covering topics such as traditional and less toxic alternatives in industrial technology; chemical toxicity; pollution prevention case studies for industry; environmental management; and pollution prevention policy.

Work on Waste, USA 82 Judson Street, Canton NY 13617 Phone: (315) 379-9200 Fax: (315) 379-0448

Work on Waste publishes "Waste Not", the weekly reporter for rational resource management. They also provide information and expertise on the dangers of incineration, risk assessment, and other issues facing communities with waste disposal issues.



Working Group on Community Right-to-Know 218 D Street SE, Washington DC 20003 Phone: (202) 544-9586 E-mail: <u>orum@rtk.net</u> www.crtk.org

The group coordinates the community right-to-know programs of more than 20 national environmental and public interest organizations and serves a nationwide network of state groups and activists. They publish a bi-monthly newsletter, "Working Notes", covering news in right-to-know legislation and court decisions, as well as reviewing new resources for activists.

Publications

"Generations at Risk" by Ted Schettler, M.D., M.P.H., Gina Solomon, M.D., M.P.H., Paul Burns, J.D., and Maria Valenti (The Greater Boston Physicians for Social Responsibility and the Massachusetts Public Interest Research Group Education Fund, 1996)

This report brings together information about the reproductive health effects of selected chemical exposures with use and emissions data from the state of Massachusetts. Its overall finding is that while human exposure to synthetic chemicals is extensive, the information on the effects of such exposure is often unknown or incompletely studied, even with strong indications of negative health effects. The authors use their research as an argument for greater regulation of industrial chemicals, and a "better safe than sorry" policy for allowing them into the commercial market.

"Living Downstream: Cancer and the Environment" by Sandra Steingraber

(Addison-Wesley, 1997)

Sandra Steingraber, biologist, poet, and survivor of cancer in her twenties, brings all three perspectives to bear on the growing body of evidence linking cancer to environmental contamination. "Living Downstream" is the first book to bring together toxics-release data-now finally made available under the right to know laws-and newly released cancer registry data. It traces the entire web of connections between our bodies and the ecological world in which we eat, drink, breathe and work. Steingraber's outlook is hopeful throughout, for, while we



can do little to alter our genetic inheritance, we can do a great deal to eliminate the environmental contributions to cancer, and she shows us where to begin.

"Our Stolen Future" by Theo Colborn, Diane Dumanowski, and John Peterson Myers (Dutton, 1996) Picking up where "Silent Spring" left off, the authors trace birth defects, sexual abnormalities, and reproductive failures in wildlife to their source - synthetic chemicals that mimic natural hormones, upsetting normal reproductive and developmental processes. By threatening the fundamental process that perpetuates survival - ability to reproduce - these chemicals may be invisibly undermining the human nature as well. Includes a chapter on DES. "Physicians Desk Reference" by The Drug Information Services Group (Medical Economics Co., 1996) The PDR contains descriptions of prescription drugs prepared by drug manufacturers for medical professionals, including information of FDA approved uses of each drugs, dosages, possible side effects, and relevant warnings. It also includes information on possible uses of drugs outside of FDA-approved labeling, and references to scientific studies involving each drug. "Pills That Work, Pills That Don't - How to Get the Best, Safest Prescription for You and Your Family" by Gideon Bosker (Crowin, 1997) Doctors prescribe hundreds, if not thousands, of different types of drugs in their practices, and can't always know what's safest for each patient. This is the most up-todate guide on controversial prescription drugs and their safer alternatives. It provides consumers with the information to choose the prescription drugs they are comfortable with, based on all available data. "Putting Scientist in Their Place: Participatory Research in Environmental and Occupational Health" by Juliet Merrifield

(Economics Education Project Working Paper #12, Highlander Center, 423/933-3443)



Many community and workplace activists have come into headon collision with the scientific establishment in recent years of threats to people's health from toxic chemicals in the environment and workplaces. These conflicts have cast doubts on some of the most deeply embedded values of science itself, including the central concept of objectivity. This very readable monograph reviews some of the issues of control over the production and use of scientific knowledge which have come out of struggles over the past decade in the southeastern U.S., and looks at alternative approaches to a 'new' science which is responsive to people's needs and accountable to their oversight.

"Raising Children Toxic Free" by Herbert Needleman, M.D. and Phillip J. Landrigan, M.D. (Avon, 1995) Children are much more vulnerable to the dangers of pollution than are adults. Raising Children Toxic Free is the first guide for parents and physicians on how to realistically control the threat to children's health from pollution. Identifying the critical pollutants in today's environment - from asbestos and lead to radon and secondhand smoke - the authors offer practical advice on how to reduce risks at home and in larger environment, including schools and playgrounds.

"Taking Action to Stop Dioxin Exposure: Strategy Recommendations from the 3rd Citizens' Conference on Dioxin and Other Synthetic Hormone Disrupters" (Citizens Clearinghouse on Hazardous Waste) In March 1996, almost 600 people gathered in Baton Rouge, Louisiana to create the action strategies that are at the heart of this indispensable workbook. The Baton Rouge conference was designed not just to educate but also to serve as the starting point for broad based grassroots campaigns to stop dioxin exposure. No matter where you live, no matter what you do, no matter what else is going on your life, there are proposals for action in this book that you can organize. Includes chapters on "Dioxin 101" and "Endocrine Disrupters 101" as well as action campaigns for the paper and pulp industry, manufacturing and cleaning, incineration, PVC, food, and valuable guidelines for working with the media.

STUDY GUIDE Women Make Movies

"To Do No harm: DES and the Dilemmas of Modern Medicine" by Roberta J. Apfel and Susan M. Fisher (Yale University, 1984) This carefully balanced book studies the medical effects of DES, its psychological repercussions, and the factors that contributed to the DES disaster. The authors raise important questions about the explosion of modern medical technology, vividly delineating the factors contribution to experimentation with new techniques and drugs.

"When Technology Wounds: The Human Consequences of Progress" by Chellis Glendinning (William Morrow, 1990) Since the introduction of thousands of new chemicals in the 1940s - pesticides, herbicides, radiation, artificial hormones, food additives, toxic waste, industrial chemicals, and toxic building materials - one in three Americans contracts cancer. This book tallies the cost of unchecked technological development, and calls for reexamining our approach to progress.

"Worst Pills, Best Pills II: The Older Adult's Guide to Avoiding Drug Induced Death or Illness: 119 Pills You Should Not Use: 245 Safer Alternatives" by Sydney M. Wolfe and Rose Ellen Hope

(Pantheon Books, 1993)

The safety of some commonly used drugs is currently under debate, though your doctor may not be aware of it. This book attempts to provide people who aren't members of the medical community with information regarding the safety of some particularly controversial drugs, and possibly safer alternatives.