

## DES Archives Find a Home—and the Perfect Caretaker

Lessons from history—and the opportunity to avoid past tragedies—only endure if people can access records about them. That's part of the rationale behind a new initiative of archiving records about DES and from those exposed to DES at Smith College in Northampton, Massachusetts. Throughout the summer, the College has been collecting, processing and archiving hundreds of records with the goal of completing the collection by the end of October, using funding from DES Action USA.

"I am so pleased that the DES records are in the Sophia Smith Archives of Women's History," Elizabeth Myers, Director of Special Collections at Smith College, told the DES VOICE. "One of the SSC's collection's strengths has always been women's health, specifically reproductive health. Having a collection like DES Action adds to the complex history of women, reproduction and wellbeing."

The collection will not be digitized due to the time-consuming nature of the work and the unique, third-party privacy concerns that exist with some of the records, Myers explained. But the materials will still be listed online for anyone to find, and individuals can request copies or scans of specific records or visit the reading room in person to look through the collection. She said



*Jennifer L. Bolmarcich, pictured at the bottom left, sits with her grandmother Barbara L. Stanley and her mom Kathleen S. Craig, with her two younger brothers, David Tabor Jr. and Brendan Craig, behind them.*

the process represents how many archives projects are managed: first a contact with an individual donor, then negotiation of the deed of gift and finally delivery to the archivist who will arrange and describe the material.

"Our goal as archivists is always

to make the material accessible to researchers, and that's why we spend so much time organizing the papers and then listing them in a finding aid," Myers said. "That finding is like a map that anyone can use to better understand what is in the collection."

The person Smith found to do the actual archiving ended up with an added bonus: she is a DES Granddaughter herself. Jen Bolmarcich, a Simmons College graduate student in archives, saw the internship for a DES archivist position posted by Smith College and was immediately interested. The eight years she had spent working in a biotech laboratory after college had taught her a lot about the difficulties of managing research data and records over time and aroused her interest in

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### Finding the Right Home

The DES archive collection has familiar company at the Sophia Smith Collection that makes its new home particularly appropriate. In addition to our records, Smith College holds the archives of the National Women's Health Network, including the records of the founder of the women's health feminist movement Barbara Seaman and those of Sybil Shainwald—a lawyer known

for her litigation on behalf of DES families. Patricia Sipe, a mathematics professor at Smith College, was involved with DES Action USA and penned an essay in 1982 that's now in the collection, and in 1993, Margaret Lee Braun and Nancy M. Stuart's photography exhibit, "Exposed: The Untold Story of DES," was shown at Smith College and later became the basis for the 2001 book "DES Stories."

# JOIN THE CONVERSATION

## New Member Benefits!

Part of our upgrade to the DES Action USA website includes a new members-only area. As a member, you'll be able to log in to the Members Area for access to:

- **Rate Your Doc**—we've always offered lists of doctors that were recommended by other DES-exposed members. Now you can share your knowledge, and maybe spare some fellow members some pain, about the doctors in your area. Rate your doctor by entering his or her name, location and specialty, then add your comments: Is he or she knowledgeable about DES? Open to discussing options or fears? Tell your fellow members.
- **VOICE Newsletter**—current and historical. The VOICE is the most popular member benefit of DES Action. Now access all 36 years of newsletters and search for any topics or articles you

need. The VOICE documents the history, the science and the personal stories of DES and all of us who were exposed.

- **Attorney List**—If you're interested in getting involved in possible future DES-related litigation, we offer a list of knowledgeable attorneys DES Action members have shared with us who might be able to help.
- **Exclusive Content**—an expanding collection of articles and videos accessible only to current DES members.

**And more!** Update your mailing address, pay your membership dues or make a donation online.

## DES Action USA on Facebook

Like DES Action USA on Facebook and follow us on Twitter to stay up to date on medical and environmental health news that affects you, your loved ones and the planet. Share your thoughts with an engaged and active community. There's a ton of

information swirling online 24/7 that affects the DES population—don't let it pass you by!

## Online Support Group for DES Daughters

Here is a safe place for discussing very personal issues that arise for DES Daughters. We live in the farthest reaches of the country but have developed a sense of community together, via our email listserv.

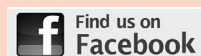
What we talk about is private—just between us—so we can feel free to raise questions on topics we aren't comfortable bringing up with others. What is amazing is the depth of knowledge in the responses.

It's a terrific resource for information and support from DES Daughters who wrestle with the effects of menopause, family relationships and medical diagnosis issues specific to DES exposure. To join the support group, send an email to: [DESActionDaughters-subscribe@yahoogroups.com](mailto:DESActionDaughters-subscribe@yahoogroups.com).

## New Website Information

We're changing to a new membership program to improve our service. The big thing to know is that we've reset the passwords. The new default password is: **desUSA?&B5V**

You'll find the same great content: a searchable list of doctors, a list of lawyers, and back issues of the VOICE in flipbook and pdf formats.



## MISSION STATEMENT

The mission of DES Action USA is to identify, educate, empower and advocate for DES-exposed individuals.

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# Hysterectomies, Fibroids and Cancer: Understanding Concerns with Power Morcellation

Many DES Daughters have had a hysterectomy or a myomectomy, which removes fibroids. DES Daughters are 12% more likely to have fibroids than those not exposed, and the fibroids tend to be larger than average. If you had a minimally invasive surgery like these before 2014, your surgeon may have used a laparoscopic power morcellator. These medical devices divide up tissue into small fragments and make it easier to remove.

But regulators learned in 2014 that laparoscopic power morcellation can potentially spread around unrecognized cancerous tissue. If a woman had a cancerous tumor in her uterus that hadn't been found yet, power morcellation could have spread that cancer outside the uterus. That could stimulate cancer growth elsewhere in the body, putting the woman at greater risk of death. Most women who got a hysterectomy or myomectomy before 2014 would not know if their procedure involved laparoscopic power morcellation.

"Any more than a doctor would tell you what scalpel he's planning on using, it's unlikely that the doctor would have told you he was going to morcellate," said Stephanie O'Connor, an attorney with Douglas & London in New York City who represents women whose surgeries involved morcellation. "If you had any operation from 1998 to 2014, it's quite possible that a morcellator was used despite what you were told."

The risk of cancer spread was rare, but morcellation is not necessary for these procedures. Therefore, in 2014, the U.S. Food and Drug Administration

issued a warning against using laparoscopic power morcellators in women undergoing a hysterectomy or having uterine fibroids removed. The warning applied particularly to women who had entered or completed menopause or who required a large amount of tissue to be removed. Now that this warning has been in place for two years, researchers have looked at the current rates of morcellation use.

In a *JAMA* study in August, researchers investigated the outcomes of all women, ages 18 to 95, who underwent a hysterectomy from 2013 through early 2015 at any of approximately 500 hospitals. Among more than 200,000 women who had a hysterectomy during that time, 117,653 women underwent a minimally invasive procedure. The rate of minimally invasive hysterectomies dropped four percentage points. Morcellator use dropped even more, from 13.5% in early 2013 to 2.8% in 2015.

The complication rate in minimally invasive hysterectomies remained the same over this time—and so did the rates of uterine cancer, other gynecologic cancers, rapid unnatural cell growth on the endometrial tissue, and uterine tumors. Therefore, it did not appear that using morcellation less made any difference in cancer rates, but cancer spread through morcellation is rare enough that any decreases in risk may only show up in a much larger group of women.

"Whether or not cancer is found, you are at risk of migrating tissue—wandering or parasitic fibroids," O'Connor pointed out. "Monitor your health closely and if

any follow-up is necessary, get and keep the records." To get records, she recommends developing a good relationship with your gynecologist and requesting the surgical records that explain the procedure's process. These records will include a "gross inspection," describing what the doctor could see. You should also request the pathology report always done on sample tissue after the operation.

Another study last year in *JAMA Oncology* specifically looked at cancer risk related to myomectomies performed in more than 41,000 women from 2006 through 2012. The uterine cancer rate was 0.19% in those with non-morcellation surgeries and 0.09% in those with procedures with morcellation. Therefore, cancer rates were not higher in those with morcellation.

Still, to remain cautious, morcellation should not be used in hysterectomies or myomectomies. In April, the FDA approved a new "containment system" that can be used "to isolate uterine tissue that is not suspected to contain cancer." The product, called PneumoLiner, has not been shown to reduce the risk of spreading cancer during hysterectomy or myomectomy, though.

"This new device does not change our position on the risks associated with power morcellation," said William Maisel, MD, the deputy director for science and chief scientist at the FDA's Center for Devices and Radiological Health. "We are continuing to warn against the use of power morcellators for the vast majority of women undergoing removal of the uterus or uterine fibroids."

 **DES VOICE**



# New Chemical Safety Act Addresses Flaws in Existing Law

If it were necessary to pick the single biggest reason that millions of women were exposed to DES, it would be the poor regulation of drugs and other man-made chemicals all those decades ago. In the years since, the federal government has greatly improved the regulations that require extensive testing of medications and other pharmaceutical products, but that does not mean laws are as tough as they could be.

Despite big strides in regulating compounds in agriculture, plastics, food production, industrial manufacturing and other major industries, the Flint lead water crisis in Michigan revealed the gaps in enforcement. It's also difficult for Congress to keep up with rapid changes always occurring in manufacturing. It took almost no time at all after bisphenol A (BPA), for example, was removed from several products that manufacturers began instead using bisphenol S (BPS), a nearly identical compound whose effects on human health are much less understood. Such substitutions could be jumping from the frying pan to the fire without adequate scientific study.

Now, a new law is aimed at giving regulators an edge. The Frank R. Lautenberg Chemical Safety for the 21st Century Act became law on June 22, 2016, with support from both major political parties in the U.S. House of Representatives and the Senate. The law took effect immediately and makes significant and long-needed changes to the Toxic Substances Control Act, the main law that governs how the Environmental Protection Agency manages chemical substances and mixtures.

"EPA views the law as a major victory for chemical safety, public health and the environment—particularly the mandatory duty to evaluate chemicals and the new risk-based safety standard," the EPA states on its website. The agency announced that it is "already taking steps necessary to carry out its new responsibilities, including identifying those chemicals actively in commerce, establishing procedures to prioritize chemicals and evaluate high-priority substances, and working with stakeholders on setting up a fee system to support implementation."

Now 40 years old, the original toxic substances law addressed "the production, importation, use, and disposal of specific chemicals including polychlorinated biphenyls (PCBs), asbestos, radon and lead-based paint," according to the EPA. This regulation included testing chemicals if someone had identified risks of concern, maintaining the inventory of more than 83,000 chemicals used in manufacturing or in imported goods and to ensure adequate record-keeping related to these compounds.

But the previous law fell short. "Even with the best of intentions, the law didn't quite work the way it should have in practice," explained President Barack Obama in his remarks when he signed the bill. "In 1976, some 62,000 chemicals were already on the market. But the law placed demands on the EPA that were so tough, so onerous, that it became virtually impossible to actually see if those chemicals were harming anybody." Only five of those chemicals were ever banned, Obama added.

The old law also didn't specify

how consumers could learn more about the composition and testing of different substances and how long a chemical could sit on the shelf before the EPA had to investigate its safety.

"The new law requires EPA to make an affirmative finding on new chemicals or new uses of existing chemicals before they can proceed to the marketplace," the EPA explained in an FAQ online.

The Lautenberg Act also requires the EPA to evaluate chemicals that already exist, now with clearly established and enforceable deadlines. All chemicals currently used in commerce must now undergo EPA investigation, starting with the compounds most likely to present risks to public health. For new chemicals, the EPA must evaluate them with a new "risk-based safety standard," particularly in terms of safety for vulnerable populations, such as children, pregnant women and the elderly.

In particular, the law expedites evaluations of five specific chemicals that include two flame retardants, two rubber-manufacturing chemicals and an antioxidant used in oil, gasoline and lubricants.

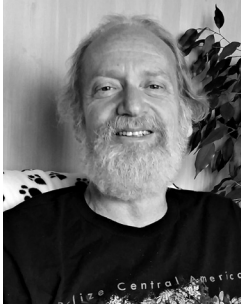
Finally, the law also gives the EPA the power to remove some of the unjustified confidentiality protections that could previously be used to prevent the public from learning about different chemicals, and it includes consistent funding to pay for all of this new regulation. At last, the EPA is not only required to begin examining the tens of thousands of chemicals developed in the past several decades, but it has the resources and the teeth to do so.

DES VOICE

# Q&A with a DES Action Member: One Man's Journey

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*Individuals join DES Action for different reasons, and they come from a wide range of different backgrounds. With so much DES research focused on Daughters, Sons are often neglected despite needing as much support. For this issue, we asked Tom Shrifter, a DES Son, to share his perspective.*



Tom Shrifter

**Q: Can you describe the experience of discovering you were exposed to DES?**

**A:** The first time was while I was in college, when a doctor looked at me and asked me if I was exposed to DES. At that time, I didn't know what DES was, and then I asked my parents if I had been exposed to it. My parents at that time told me no. It wasn't until many years later that my parents, under pressure, admitted that there was a chance that it had been used because there had been five miscarriages between my older brother and me, and this was 1957.

My parents were in denial for many years, and then my mother's favorite refrain to me was "At least you're alive." Of course, by the time my parents said there was a chance, the OBGYN doctor had passed away, and his records had been destroyed. How did I feel? Angry, betrayed, ignored.

**Q: In what ways have you been affected by your DES exposure?**

**A:** The ways that I have been affected by DES stem from my

genitals being deformed. When I was about 5, if I tried to urinate, it hurt intensely. It burned and stung. After several X-ray tests, they found out that the tip of my urethra was barely open, so they had to do surgery to open it. When I was a teenager, I noticed that I had difficulty maintaining an erection. I was extremely shy and reserved, especially knowing that I would disappoint in sex. Not until recently did I find out that my valves weren't closing, and I finally had confirmation that it was a physical problem. I spent many years in therapy and always wondered if it was a physical problem. Today I am 59 years old. I had to have an implant put in to correct the valves, and I am using testosterone injection because if I didn't, I would barely have any testosterone.

**Q: How did you find out about DES Action USA and what led you to join?**

**A:** A couple of years ago, I was doing research about DES online, mainly to see if there was any support, and DES Action USA came up. I wanted support. This has been very difficult for me to go through, and I was looking for people that had gone through something similar.

**Q: Can you describe what it's like to be a DES Son when so much of the research focuses on effects on DES Daughters?**

**A:** What it's like has been

horrible. I do feel that DES Sons have been lost in the shuffle, and there is very little research. The medical community has been seriously lacking and insensitive. I went to a so-called DES specialist doctor in San Francisco, and all he would tell me was that he was recently in Africa and the male lion had a small penis, too. And he wouldn't confirm for me that I could have been exposed to DES. He was afraid that I would want to sue. When I try to talk to doctors about DES, all they say is there isn't anything that can be done. Well, I wish I had known years ago this implant could have fixed my problem. But I know that hormonally, there isn't anything that can be done and I'll be on testosterone the rest of my life.

**Q: If you could make one improvement to DES Action USA, what would it be and why?**

**A:** I would like to see more info for DES Sons and possibly a DES Sons support group. I like reading the DES VOICE, and it has good info. I hope to see more information for DES Sons. In the future, I hope we will gain more research for DES Sons. I also believe the medical community has to give more support, not just denial.

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*If you would like to see DES Action start a DES Sons listserv, please email [info@desaction.org](mailto:info@desaction.org).*

moving toward that field.

“My concentration in archives has taught me to manage and preserve both physical and digital records, and most importantly, to provide access to the stories those records tell,” Bolmarcich said. The combination of archiving, the topic

uncle’s pregnancies. Although the doctor never contacted Bolmarcich’s grandmother, she heard about the problems with DES on the news and notified her son and daughter.

“My grandmother’s not sure when that discussion happened,” said Bolmarcich, who talked to her grandmother about her

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**“It’s been a unique opportunity to be able to lend my professional skills to something so personally relevant, and so it has been both personally and professionally rewarding.”**

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area of DES and the opportunity to work in the Sophia Smith Collection were a combination too alluring to ignore. “I believe both my personal interest in the material, as well as my science background and other archives experience, made me a good candidate for the job,” she said.

Bolmarcich’s story is one that other DES Granddaughters may recognize, starting with a premature birth at 25 weeks due to the prenatal effects of DES exposure on her mother’s cervix. Fortunately, the experience of her birth meant her mother was able to seek preventive care to avoid premature births with Bolmarcich’s siblings. Her mother had a cerclage that held, and Bolmarcich’s siblings were born at term.

“I happened to be very lucky, and have not had any major problems from my prematurity save a mild nonverbal learning disability and ADHD,” Bolmarcich said. “Being a DES Granddaughter has meant being especially aware of both the risks and benefits of medicine.”

Her grandmother had had several miscarriages in her earlier pregnancies, and she took DES during Bolmarcich’s mother’s and

recollections for this article. “My mom doesn’t recall being aware of her exposure until after my birth in 1981. As DES Action was pursuing awareness campaigns around that time—the first national DES Awareness Week was in 1983—it’s quite possible that DES Action’s work was responsible for the news coverage my grandmother remembers.”

She said the experience of archiving DES records has also offered insights into her own life.

“I think the most interesting part for me, personally, as a lesbian woman, has been discovering the experiences of transgender DES Children and of the research on gender identity and sexual orientation among DES Children,” Bolmarcich said. “Discovering this aspect of the DES experience has given me another connection to the collection and community.” She specifies use of the term DES Children because records identifying individuals as DES Sons may no longer be accurate since being AMAB—assigned male at birth—is not the same as identifying as a male. “Children” captures any individual exposed to DES in utero, whether second or third generation.

She described two particular things in the collection as her favorite items. One is a photo album of pictures created after an early meeting, seemingly in the late 1970s, with funny captions and general silliness. “It’s a wonderful glimpse of good friends having fun, while doing great work,” Bolmarcich said. Another is “Eli Lilly’s Dirty Tricks”—the name of a folder full of news clippings and correspondence whose name she kept in the official collection labelling because of “its honesty and sass.” She said the experience of working on the collection has been wonderful.

“It has been a great privilege to work with this rich material,” she said, adding that Pat Cody, Fran Howell and Kari Christianson’s amazing work assembling and maintaining material across multiple moves and transitions has been key to the archives’ success. “It’s been a unique opportunity to be able to lend my professional skills to something so personally relevant, and so it has been both personally and professionally rewarding.”

Other educational elements to the work have included working with a variety of formats and media in organizational records and carefully considering and evaluating medically sensitive correspondence.

“The main challenge with the DES Action records is issues of privacy,” Myers said. “At its core, the records reflect the medical histories of individuals and their family members. We work diligently to make sure the privacy of individuals is respected and honored. At the same time we want to provide the widest possible access to the materials. This requires a complex and repeated consideration of the law, ethics, and archival best practices.”

Anyone wishing to publish work using the collection,

Bolmarcich explained, must change or anonymize names, with the exception of the DES VOICE and published media stories. “Also, in accordance with the Society for American Archivists’ Code of Ethics, any especially sensitive correspondence concerning health information (often that of children or grandchildren) has been separated, and will be restricted for twenty years before being opened to researchers,” she said. “This

material is only about 5% of the total collection, and as the Code of Ethics states, we protect the privacy of ‘individuals and groups who have no voice or role in collections’ creation, retention, or public use.”

Bolmarcich expressed gratitude for the generosity of the board in funding her position since she would have been unable to take on an unpaid position, and she emphasized that the stories of the DES family, Daughters, Sons and

Grandchildren, are “well cared for and are a resource for everyone,” a sentiment echoed by Myers.

“The DES Action records are here for them, as they are for anyone interested in the subject,” Myers said. “By accepting the stewardship of the records, we hope to make them available for research in perpetuity, thereby ensuring that the experience of those exposed to DES remains a part of our human history.” **DES VOICE**

## Progress on DES Follow-Up Study Continues

**R**esearch about DES is not being published as frequently as it once was, but that doesn’t mean it’s not still moving forward. The sixth questionnaire in the DES follow-up study recently went out to all participants so that lead investigators Rebecca Troisi and Bob Hoover could continue to sift through the data looking for patterns that offer insights into DES effects. Begun in 1990, the follow-up study has continued to track the women in the original study begun in 1975, with questionnaires going out every three to five years to DES Daughters and the matched cohort of unexposed women.

“People don’t always know how important it is. Having responses from both groups of the participants is so important,” said Kari Christianson, one of the participants in the study. She borrowed the analogy Hoover sometimes uses: “It’s like panning for gold. You dip down and sift out and hope there’s something to learn, but maybe all you get is silt,” she said. “They know they’re not asking all the right questions, but they’re asking important questions. That’s the hard part of any kind of epidemiological study where you have a potential for such a broad range of effects.”

The main focus of the ongoing

study continues to be addressing concerns about elevated cancer risk, Troisi told the VOICE, particularly looking out for clear cell adenocarcinoma as women age. But it’s not the only goal.

“Another aim of the study is to monitor whether risk of other health conditions are altered in the DES exposed, including now the granddaughters of the women who took DES in pregnancy,” Troisi said. “The questionnaire includes a list of conditions and diseases where the participants can indicate a health professional’s diagnosis, and there is space to write in other health issues that they have experienced.”

So far, this information has

Given the recent renewed interest in possible links between DES and sexuality and gender, the questionnaire included a question about self-identified gender for the first time as well as a question about sexual orientation. Christianson also mentioned questions about prescription and non-prescription hormones women may be taking, particularly as DES Daughters are entering their perimenopausal and postmenopausal years.

But the study’s findings are only as good as the data the researchers receive: the higher the participation rate in returning questionnaires, the more scientifically valid the research findings are.

“We have been very fortunate

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**“It’s like panning for gold. You dip down and sift out and hope there’s something to learn.”**

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revealed higher rates of self-reported heart disease and diabetes in DES-exposed women, though not men, compared to unexposed individuals. “This spurred an effort to obtain physician’s reports of these conditions to follow up on the findings,” said Troisi, adding that they are preparing a study to be published on this topic.

that both DES exposed AND unexposed participants have so generously participated,” Troisi said. “Out of their sometimes tragic experience, they have contributed to not only the safety of later generations, but to a more thorough understanding of how important the earliest period of life can be for future health.” **DES VOICE**





# VOICE

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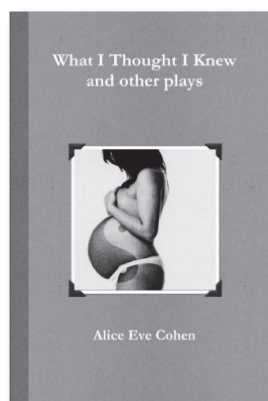


## What I Thought I Knew

**By Su Robotti**

Many DES-exposed know Alice Eve Cohen from her memoir, "What I Thought I Knew," which dealt with the pregnancy and birth of her daughter. As a DES Daughter, Alice had been told she would never be able to get pregnant or carry a baby to term. Alice is not only a writer, but also a solo performer. She has turned the memoir into a play of the same name and included it in a new book of four one-woman plays she has published, "What I Thought I Knew and Other Plays." Two of the plays are DES-related, while the other two are not overtly related to DES.

One play in the group, "Jessica's Cervix," addresses some of the issues we DES-exposed have faced. The play centers on an internal



exam of Jessica's DES-damaged cervix, which is being videotaped. Even though Jessica agrees to be filmed, she is unprepared for the inhuman element the camera brings in. Her feelings, nerves and even her questions are shushed by the doctor as he examines her cervix as if it weren't attached to a human, much less to the person

trying to talk to him.

The play "What I Thought I Knew" is autobiographical, tracing the journey of a woman who had grown to be comfortable in her DES-damaged body and in her life. Then a medically impossible pregnancy, which goes undiscovered by doctors for five months, proves to her that she knows nothing of herself and what she is capable of handling. "What I Thought I Knew" received a Jane Chambers Playwriting Award honorable mention for feminist plays, and was an O'Neill National Playwrights Conference finalist.

Alice Eve Cohen's plays are painful and familiar to anyone with DES exposure and damages. They are universal to anyone who has been badly treated by medicine—which is too many of us.