

Tell Your Children About DES

By Fran Howell

Talking about DES may be one of the most important things you do with your children, and it will be time well spent.

In the early days of DES Action we mounted a successful campaign urging individuals born between 1938 and 1971 (and beyond) to Ask Your Mother about DES. Many of you probably still remember it. Now, as our organization moves into its fourth decade, it seems appropriate to evolve this effort into a new and equally important phase: Tell Your Children.

Those who were exposed to DES, either before birth or as grandchildren, have a right and certainly a need to know it is part of their health

histories. They then can have recommended health screenings and can make informed medical choices, especially in relation to the use of extra hormones.

Telling children about their DES exposure is not easy, acknowledges respected women's health care provider, Candy Tedeschi. "Over the years mothers have told me they didn't need to tell their DES Daughters or Sons, as long as their children were healthy and had no medical problems from their exposure. If any problems developed, THEN they would tell them."

But Tedeschi points out the flaw in that logic, "What happens if the time is never right or something happens to you, or your child doesn't tell you

about a problem that developed in adulthood?"

So the time to have a conversation about DES could be now for DES Mothers who haven't yet told their children. It also might be the right time for DES Daughters and Sons, if their children are now teenagers.

DES Action member and Clinical Psychologist Linda Bortell, Psy.D., suggests having the discussion at an age appropriate time, perhaps just prior to the first gynecological exam or when potential health issues might come up for this age group.

"Keep it simple and straight forward," says Bortell. "DES was something grandma was given. She did a good job and did what her doctor told her to do. There isn't a lot of research yet into how it might affect you, but you should know about it. When you see a doctor, say you are a DES Grandchild."

According to Bortell, "Talk about DES with a sense of empowerment - this is who you are and it doesn't have to define your life, but it is important information you need to know." She adds, "There is no shame in it, and no one did anything wrong, except the drug companies."

Friction between parents and children, especially between mothers and daughters, is legendary. Planning what you say is a good idea. Then understand that your child may become angry at the news. Bortell says that's natural.

Explain that you didn't ask to be DES exposed, nor did grandma, but

Yoplait: Hypocritical Yogurt

By Kari Christianson

Breast Cancer Action has launched a campaign requesting that General Mills, the producer of Yoplait yogurt not use milk from cows treated with the genetically engineered hormone, rBGH (recombinant bovine growth hormone). Research has linked the use of rBGH to a stimulation of another naturally-occurring hormone found in both cows and humans; this hormone stimulation may increase the risk of breast cancer.

While other yogurt producers also use genetically engineered milk, Yoplait has promoted its *Save Lids to Save*

Lives campaign. It asks consumers to send back pink lids to the company to prompt a donation from General Mills for breast cancer research. The irony is not lost on Breast Cancer Action — or DES Action.

DES Action endorses the Breast Cancer Action campaign, which represents our continuing concerns about rBGH and human health.

Questions about rBGH are not new to DES Action. In the mid to late 1980s, we worked with many other organizations to demand the FDA evaluate human health safety before approving rBGH. This has not been done in the 22 years since

continued on page 3

continued on page 3



DES Action USA
187 Via Catalunha
Jupiter, FL 33458

desaction@comcast.net
www.desaction.org

Yes!—I want to join DES Action to stay informed and support a cause I believe in.

All members receive **The DES Action Voice** quarterly. Those at the **\$100 level and above receive an annual report on DES Action's work and progress.** All contributions are **tax deductible.**

- | | | |
|--|---|--|
| <input type="checkbox"/> Member: \$40 | <input type="checkbox"/> Supporter: \$100 | <input type="checkbox"/> Sustainer: \$500 |
| <input type="checkbox"/> Sponsor: \$50 | <input type="checkbox"/> Associate: \$200 | <input type="checkbox"/> Benefactor: \$1,000 and above |
| <input type="checkbox"/> Friend: \$75 | <input type="checkbox"/> Patron: \$250 | |

Please make checks payable to **DES Action.**

I am a: ☐ DES Daughter ☐ DES Son ☐ Other ☐ DES Granddaughter or Grandson
☐ DES Mother of a: ☐ Daughter ☐ Son

NAME

ADDRESS

CITY | STATE | ZIP

PHONE

E-MAIL ADDRESS

Join OnLine Support Group for DES Daughters

Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member you can join the DES Action Daughters On Line Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action On Line Support Group simply send a blank e-mail to:
DESactionDaughters-subscribe@yahoogroups.com

You'll receive an e-mail back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

MISSION STATEMENT

The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals as well as educate health care professionals.



Published quarterly by:

DES Action USA
187 Via Catalunha
Jupiter, FL 33458
ISSN 1522-0389

1- (800) DES-9288 (800) 337-9288
desaction@comcast.net
www.desaction.org

Executive Director
Fran Howell

Program Director
Kari Christianson

**VOICE Editor
& Research Liaison**
Pat Cody

Board of Directors
President: Patti Negri
Vice President: Karen Fernandes
Secretary: Ann Giblin
Treasurer: Kim Mazeres
Michael Freilick
Cheryl Roth
Litsa Varonis

VOICE Design and Layout
Solunar Graphics, Columbus
(614) 488-9962

Printing
CPMM Services Group, Columbus
(614) 447-0165

Contributors
Kari Christianson
Pat Cody
Dee Hansch
Fran Howell
Patti Negri

© 2008 DES Action USA

DES Action Contacts

United States

**DES Action
USA National Office**
187 Via Catalunha
Jupiter, FL 33458
desaction@comcast.net
www.desaction.org
800-337-9288

DES Action Sons Network
104 Sleepy Hollow Place
Cherry Hill, NJ 08003
msfreilick@hotmail.com

**DES Action
Generations Network**
desactiongen@optonline.net

DES Action Massachusetts
14 Canterbury Dr.
Canton, MA 02021
aeq5ct@verizon.net

DES Action Pennsylvania
Box 398
Nescopeck, PA 18635
www.desactionpa.org

DES Action Los Angeles

6324 Ivarene Ave.
Hollywood, CA 90068
Pinkkaire@aol.com

DES Action International

Australia
DES Action Australia, Inc.
PO Box 282
Camberwell 3124 Vic. Australia
info@desaction.org.au
www.desaction.org.au

DES Action Australia - NSW
14 Edmundson Close
Thornleigh NSW
2120 Australia
C_devine@bigpond.net.au

DES Action Canada, Inc.
5890 Monkland Avenue
Suite 15
Montreal, Quebec Canada H4A 1G2
(514) 482-3204
1-800-482-1-DES
desact@web.net
www.web.net/~desact

England

DES Action UK
Box 128, Blaydon LDO, NE40 3YQ
England
info@des-action.org.uk
www.des-action.org.uk

France

Reseau DES France
12 rue Martinon
40000 Mont de Marsan
France
reseaudesfrance@wanadoo.fr

DES Action Ireland

Carmichael House
North Brunswick St.
Dublin 7 Ireland
info@desaction.ie
www.desaction.ie

The Netherlands

DES Centrum
Wilhilminapark 25
3581 NE Utrecht
The Netherlands
des@descentrum.nl
www.descentrum.nl

Tell Your Children *from page 1*

in a matter of fact way, discuss how you feel. Then reinforce the message that you may not be able to protect the child from everything, but you will be there to help in any way possible.

“Admit you don’t have all the answers, but in a very matter of fact conversation tell your children they were exposed to DES and if they want to read more about it you can help them with books and web sites. Let them know you aren’t going to drop this news on them and walk away.” Consider a DES Action membership for your child when she/he leaves home.

For adult DES Granddaughters, Bortell says you can follow up by asking if they’ve been to the gynecologist

recently. “Tell them you are asking because you care, not because you want to nag.”

DES exposure hits us right at the core of our being, so this is a conversation to have in private with your child. Perhaps while driving, having lunch out together, or at bedtime. “Choosing a time and place where you both feel comfortable is crucial,” says Bortell.

Recently, a DES Daughter told us that her mother asked if she had access to good, current DES information. She was happy to tell her mom — without a moment’s hesitation — she is a DES Action member, so she is up to date on DES. That family certainly has it right.

DES VOICE



**Give Your Child
a Gift of Knowledge**

*Perfect For Those No Longer
Living At Home*

**Order A DES Action
Membership**

*Send \$40 with the name
and address to:*

DES Action USA
187 Via Catalunha
Jupiter, FL 33458

Discussing DES With Your Child

By Linda Bortell, Psy.D.
Clinical Psychologist and DES Daughter

When: Best during teen years

Where: Comfortable location for both of you, such as while driving, having lunch out, or before bed

What: Stick With The Facts:

- You are okay now
- You need to monitor your health
- No one did anything wrong (except drug makers)

How: Talk with a sense of empowerment. “DES doesn’t have to define your life — it didn’t define mine. No reason to feel ashamed. It’s important to stay up on the latest research and have your gynecological exams to make sure everything is okay.”

Understand: This is emotional and difficult for both you and your child. There could be feelings of distress or anger. Reiterate the importance of DES information so the child can begin taking control of her/his health. Stress that you are sharing this because you care — not to scare. You may not have all the answers, but you will be there through the years for your child with information and support.

Acknowledge: While you cannot always protect your child, you can help in any way possible. That includes providing books, web sites and even a DES Action membership when your child leaves home.

Yoplait *from page 1*

we first gave a presentation at a conference at the University of Wisconsin-Madison, the primary site of the Monsanto research team which developed rBGH.

Here are a few paragraphs from the 1986 article in VOICE #31.

“I’m here today representing the voice of the consumer and the voices of specific experience with a previous growth hormone — DES, diethylstilbestrol — a synthetic estrogen. As a recipient of what was the hormone technology of a generation ago, I know firsthand the danger of assuming that a hormone is safe — until years down the road when the truth and the deadly health consequences become known. DES is a pharmaceutical tragedy of unequalled proportions in this country. But I recognize that there are lessons to be learned from the tragic legacy of DES use that can be applied to rBGH development.

“I’m not convinced by the argument that rBGH is safe and does not affect cows or humans because it is a hormone that occurs naturally in dairy cows. Estrogen is a hormone that occurs naturally in women, but we now know the consequences of administering additional synthetic hormone to pregnant women. Substitute the word ‘biotechnology’ (or genetically

engineered) for ‘synthetic’ — what you have is giving more hormone to the animal than is naturally produced by that body.

“I’m suggesting — demanding — that we evaluate the health impact and potential consequences before we allow this product of biotechnology to reach our food supply. Do tests exist that can trace residues of rBGH in milk? And who sets the standard for safe limits of residues? Will we let the pharmaceutical industry, those with a financial stake, dictate levels of safety? Federal and state regulations are ignored or non-existent in dealing with the issues of testing and sale.

“The irony of this situation, of course, is that we consumers do not want rBGH in our food supply. But, if it seems that we are to be dragged kicking and screaming into the age of biotechnology in food and the use of rBGH, then let us demand all the answers. It is appropriate that we ask these questions about human health safely. And it should be mandatory that answers are provided before any ‘new’ hormone residues are introduced into the human food supply.”

To learn how all of us can be involved in Breast Cancer Action’s *Tell Yoplait: Put a Lid on rBGH!* campaign, visit www.bcaction.org.

DES VOICE

DES ACTION

In the earliest years of DES Action, when there still were East and West



Coast offices for the organization, the first person most DES Daughters talked with or received a letter from was **FAY COHEN**. Fay

staffed a national DES Action office, located at Long Island Jewish – Hillside Medical Center, from the very start of the organization. In this office, right next to Candy Tedeschi and the LIJ screening center, Fay answered the phones, counseling thousands of DES Daughters, Mothers and Sons, and did any writing and outreach needed. She worked with Dolores Wallgren and others in 1980 to develop the first brochure for DES Sons. This DES Mother with her quiet, steady presence provided the information and support needed for thousands of DES-exposed individuals to receive appropriate health care.

Kari Christianson

DES Action Program Director

DOLORES WALLGREN is a founding member of the DES Action



group in Washington, DC. A DES Mother, Dolores was the voice of DES Action and the millions of DES-exposed individuals in the United States at countless Con-

gressional hearings and meetings with government officials. As the director of DES Action activities in Maryland, as well as Washington, DC, she and the group were successful in advocating for legislation that funded a public education campaign in Maryland and prevented insurance discrimination

against those exposed to DES. With Fay Cohen and others she wrote the first DES Sons brochure. An outspoken advocate and activist, she was an early board member of DES Action and served as vice president with insight and passion.

Fran Howell

DES Action Executive Director

FRAN HOWELL may credit her mother with keeping her connected to DES Action for years, but now it's Fran who brings the best in communication and organization to everyone who contacts DES Action. With years of reporting and public relations experience,



she first served DES Action as a board member and later as the media relations specialist for DES Action during the CDC's DES Update campaign in 2003, working with dozens of publications in achieving national attention. She was named Executive Director four years ago, the first DES Daughter to serve in this position. Her gifts of relationship-building and writing about the most complex DES health issues provide a clear voice for all DES-exposed individuals.

Kari Christianson

DES Action Program Director

DIANE ANDERSON has a kind voice — and one that most DES Daughters hope they never have to hear. Working with Arthur Herbst, M.D., she is the Program Administrator of the DES Registry, officially named the Registry for Research on

We set out to recognize 30 sp

Anniversary year. Our only proble

because so many individuals have

along the way. It turns out we c

five more heroes than we'd plan

advocating for the DES communit

our heroes for their contributi

together for as long as



Hormonal Transplacental Carcinogenesis, at the University of Chicago. This is an international research registry of cancer patients with clear cell adenocarcinoma (CCA) of the

vagina and/or cervix or other specific gynecologic cancers. She is an accessible and knowledgeable resource for women reporting CCA or other reproductive tract cancers and is tireless in advocating for cancer reporting. As a member of the National Cancer Institute DES Follow-up Study, she is a researcher with a human touch in understanding the overwhelming concerns of DES Daughters with cancer.

Kari Christianson

DES Action Program Director

After her clear cell adenocarcinoma diagnosis at age 25, **JUDITH HELFAND** created a video diary of

ON HEROES

Special people during our 30th anniversary was in whittling down the list, we shared their talents and energies. I couldn't do it and ended up with a list. But that's just fine, because this is truly a group effort. We thank our members and look forward to working with you. DES Action is needed.



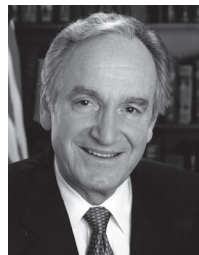
her experiences as a DES Daughter. The wrenching struggles she and her family endured came to life in the Peabody winning film, *A Healthy Baby Girl* (1997).

The movie, still showing on the Sundance Channel, helps spread the word about DES. When it airs, DES Action sees a spike in requests for information. This passionate and tireless activist turned her anger into action by co-founding Working Films, which connects independent producers with community organizers, and Chicken and Egg Pictures, which helps female filmmakers document environmental and social justice issues. The tragedy of DES spurred Judith to make the world better, and it's working.

Fran Howell

DES Action Executive Director

SENATOR TOM HARKIN and **REPRESENTATIVE LOUISE SLAUGHTER** are long-time mem-



bers of Congress who sponsored our first DES Education and Research bills in the Senate and House. These bills were signed into law 16 years ago and funding for them has remained steady, thanks to the oversight provided by Sen. Harkin and Rep. Slaughter. The DES community is profoundly grateful to them for provid-

ing the path to both research and public education about DES.

Pat Cody

DES Action Co-Founder

MICHAEL LONDON is a true champion. In representing DES Daugh-



ters, and others, he has shown he is unafraid of handling tough cases. Michael became my attorney as I pursued claims against drug companies that sold DES. While Michael's website

lists many of his outstanding accomplishments, I can simply add that I have profound appreciation for him as an advocate, colleague and human being.

Dee Hansch

DES Action Member

DEBORAH WINGARD, PH.D., Professor of Epidemiology at the University of California, San Diego,

is a DES Daughter with a keen interest in looking at what health effects



Daughters may find. She designed, and analyzed, surveys of DES-exposed who were reached through the VOICE. We printed these results in the VOICE and they were also

published in the *Western Journal of Medicine* in 1988. Deborah has a special interest in reproductive health and has many journal articles on that concern. The breadth of her research, shown in over 200 essays, ranges from diabetes to heart disease to osteoporosis and, more recently, post traumatic stress among Iraq veterans.

Pat Cody

DES Action Co-Founder

We wouldn't be here without you. Our **MEMBERS** have kept DES



Action strong for the past three decades to advocate for all who were exposed to DES. Very few grassroots organizations have been around as long as we have,

in part because they don't have the members we do. You are, without a doubt, loyal, certainly generous, and definitely committed to keeping DES research and education going. There is strength in numbers and we thank our members for sustaining us through the years. You keep DES Action a vital voice for the DES community.

Fran Howell

DES Action Executive Director **DES VOICE**

DES ACTION'S BIG ANNIVERSARY BASH

Memorable Evening And Fundraising Success

By Fran Howell

Thirty years — and we've never had a party like this! One member expected something simple, like chips and fruit punch, but this was an occasion worth celebrating. And DES Action did it in style, thanks to our generous sponsors.



DES Action Board and Staff come together around the cake

When the elevator door slid open to the New York City Fire Museum's third floor ballroom many guests gasped at what they saw. Brick walls and hardwood floors set the lovely scene. Waiters passed around an incredible assortment of hors d'oeuvres, a spectacular cheese and fruit display was front and center, and talented musicians donated their time and CD sales to help make the evening a huge success.

It was a night of families, friends and meeting others in the DES community. No one balked at wearing a nametag, because so many of us were meeting each other for the first time. Nametags helped start conversations that often ended in laughter, shared stories and hugs.

Members and their families came from far and wide. Joyce Bichler, now from California, brought her New York family members, Dee Hansch flew in from Los Angeles, Susan Bell made the trip down from Maine, as did Caitlin McCarthy from Massachusetts, so they could be with us for the evening. And we heard from many members who couldn't be there in person but were with us in spirit.

Some DES Mothers, who'd never met another one before, finally had a chance to do so. It was a special evening for them. DES Daughters could talk openly with others who knew about DES, and it felt good. DES Fathers joined the celebration and enjoyed being part of the community, while DES Grandchildren were

proudly introduced. All mingled comfortably, enjoyed the music and



Movie Producer Judith Helfand (A Healthy Baby Girl) and Screenwriter Caitlin McCarthy (Wonder Drug) meet at our party

got to know each other.

Quite a bit of interest was shown at our memorabilia table, which highlighted brochures and pamphlets dating back to our earliest years. Many guests lingered to look at the framed DES Healthy Baby Ad, which has become a familiar image to members and is highlighted on our web site home page. It was displayed next to an exquisite flower arrangement graciously donated by Danielle, at Flowers and Such.

DONORS TO THANK

We could not have had such a successful party without help from our donors, who include **Aaron Levine, Esq., Michael London, Esq., Sybil Shainwald, Esq., and Patricia Martin Stanford, Esq.** These individuals generously sponsored the party and have been ongoing supporters of DES Action through the years. Their gifts honor our three decades of work, and help pave the way



Our memorabilia table displayed brochures and pamphlets going back 30 years

for a future of action.

We also want to thank **Fred Eichler** and **Dorothy Marks** for making it possible to hold our party at the Fire Museum.

It is significant to note that this was an enormous fundraising success as well as a grand event. We brought in *more than \$8,500 in profit*, almost an unheard of amount for our small organization.

VOLUNTEERS TO HONOR

We have been fortunate in working with untold numbers of members and friends through the years – and we thank all of you! As we celebrated DES Action's 30th Anniversary we took time to honor several individuals who've volunteered their time and talents to help us along the way. We especially thank **Kari Christianson, Pat Cody, Fay Cohen, Michael Freilick, Andrea Goldstein, Libby Saks, Candy Tedeschi** and **Dolores Wallgren**.

Several guests helped us document the evening with their photographic skills. They include **Jill Murphy, Chris Vansalous, Michael Fernandes** and **Jason and Tracy Chen**. The photos you see here are thanks to their efforts.

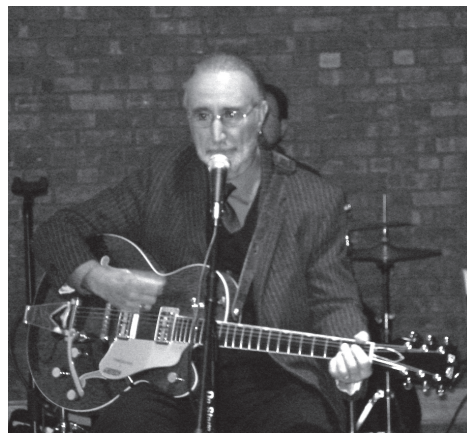
A highlight of the evening was an entertaining look at DES Action's



Former Board Members Elizabeth Wandelmaier and Barbara Tunick show off their DES Action T-shirts and Pat Cody's book

history presented by Brain Brew Entertainment. DES Action President and Brain Brew creator-extraordinaire Patti Negri guided us through historical and hysterical events — if DES Action had been around in those ancient times. Joining her were two members of her Hollywood acting team, as well as “recruited” audience members.

The evening flew by quickly with engaging music performed by Tony



The multi-talented Tony Tedeschi — and yes, he is married to Candy Tedeschi



The crowd gathered to enjoy presentations and entertainment

Tedeschi, Pedro Pereira and Doug Kwartler. We met individuals we felt we've known for years but had never met. Many of us ate too much thanks to Cocktail Caterer's outstanding spread of delectable treats.

It was an amazing celebration with everything coming together better than anyone could have imagined. We've taken time to celebrate and now we are right back to the job at hand. There is plenty to do, and a strong team in place to coordinate DES Action's efforts as we move ahead on the issues important to us all. **DES VOICE**

DES Action Provides Input In Court Case

By Fran Howell

The U.S. Supreme Court heard arguments on November 3 in a case DES Action is watching closely. A ruling in favor of the pharmaceutical industry could block lawsuits against drug companies that produced FDA-approved drugs, including DES.

Attorney Aaron Levine filed an Amicus Brief on our behalf, meaning that even though DES Action is not a party to the case, we provided information we hope the justices consider.

Our argument, in a nutshell, is that individuals should be allowed to file lawsuits concerning FDA-approved drugs, especially if the FDA failed to rigorously evaluate the drug's safety.

That is the case with DES.

Levine acknowledges the difficulty in making predictions, but after the hearing he is somewhat more reassured there may not be a total ban on such lawsuits. He thinks the Court could impose limits that DES-knowledgeable attorneys can work with.

Because several justices posed questions we'd raised, Levine speculates they may have read DES Action's Amicus Brief.

The Supreme Court ruling is expected early next year. Levine is cautiously optimistic that even if justices side with the pharmaceutical industry on most counts, there may not be a total ban on lawsuits. If so, he believes DES litigation will be allowed to continue. **DES VOICE**

DES Action USA
187 Via Catalunha
Jupiter, FL 33458

www.desaction.org

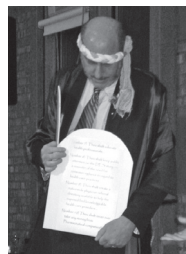
Forwarding Postage Guaranteed
Return Service Requested

Moving? Please let us know...

TEN COMMANDMENTS FOR DES ACTION

We've been hard at work for 30 years, but it took until now to officially nail down our Ten Commandments — or organization guidelines. They came to us thanks to the Brain Brew production company, headed by DES Action President Patti Negri.

During our Anniversary Party her troupe's performance included a sketch that had Moses (played spectacularly by DES Action Board Member Michael Freilick) with the Ten Commandments for DES Action. We've abided by them since the start, but now we have them in writing — not quite in stone, though.



- | | |
|--|---|
| I Thou shalt advocate for Research, | VII Thou shalt Educate Health Care Professionals, |
| II Thou shalt spread Information, | VIII Thou shalt keep Public Attention on the DES story, |
| III Thou shalt support Education, | IX Thou shalt create a Physician Referral List of docs who care, |
| IV Thou shalt support Legislative Action, | X Thou shalt Never Take Money from Drug companies! |
| V Thou shalt be (to quote Pat Cody) "Tenacious," | |
| VI Thou shalt Identify, Educate and Advocate for DES-exposed, | |

Shop Online and Donate to DES Action

What could be easier? When shopping on line, start first at www.GoodShop.com and designate DES Action USA. We get a donation for each purchase you make — at no cost to you.

The list of stores is amazing and includes Amazon.com, Apple Store, Barnes & Noble, Chicos, Coldwater Creek, Expedia, Travelocity, iTunes, LL Bean, Lands End, Staples, PetSmart, Hotels.com, 1-800-Flowers, Old Navy, Nike, Macys, etc. There are hundreds to choose from. A complete list is on the left side of the GoodShop.com home page.

Use GoodShop.com to get to a retailer's site. Then shop as usual. Please try it, and ask family and friends to support us, too. We received a \$93.91 donation this year from GoodShop.com. With your help it adds up. Thank you!

GoodShop

DES VOICE

DES VOICE