DES Action VOICE

Inside

A Focus On Diethylstilbestrol

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Alternative For Paps Is Approved

But Paps Aren't Going Away Any Time Soon

By Fran Howell

Pap smears have long been the gold standard for detecting cervical cancer. But the Food and Drug Administration (FDA) has just approved another test as a new first-line screening for this cancer. It's a test to check for the DNA of two common human papillomavirus (HPV) strains that cause most cervical cancers.

The operative word for DES Daughters though is "most," because the cancer associated with exposure—clear cell adenocarcinoma of the vagina and cervix—has nothing to do with HPV and wouldn't turn up in that test.

After the FDA advisory committee's unanimous vote recommending Pap screenings be replaced with the DNA test as a primary screening tool, a chorus of concern arose from DES Daughters who want to continue getting their annual Pap smears. The good news is that experts predict Pap screenings won't disappear any time soon.

DNA testing for cervical cancer isn't new and has been used as an adjunct screening after an abnormal Pap. The change would be the FDA allowing its use as a preliminary screening tool, which had been the purview of Paps.

What seems likely to happen is that DNA tests would join Pap smears as another tool in the arsenal against cancer—a screening option choice to be made in consultation between patient and doctor. As a result, DES Daughters should be able to stick with the older testing regime (Pap/pelvic exams) to be certain they are screened for vaginal or cervical clear cell adenocarcinoma.

Having good lines of communication with doctors will become increasingly important. Our DES Daughter TOOLKIT (Fall 2013 VOICE issue 138) is already helping many DES Daughters explain their concerns to health care providers. Extra copies are available at two for $5 and can be ordered by sending a check to DES Action USA or going online to http://desaction.org/donate.htm. Make sure to specify a TOOLKIT order and mailing address. See page 3 for What You Need To Know About Paps. DES VOICE

Researchers Seek DES Biomarker

Can a Blood Test Confirm Prenatal DES Exposure?

By Fran Howell

You cannot look at individuals and know they are DES Daughters or DES Sons, as no outward signs exist. It has long been the hope that someday tests could identify a biomarker to prove prenatal DES exposure. Now scientists are going after it.

Robert N. Hoover, M.D., ScD, is the Director of the National Cancer Institute Epidemiology and Biostatistics Program, which houses the DES Follow-up Study. Under the auspices of that study, 60 participants will be recruited to provide blood samples. Thirty will be known DES-exposed with a matched set of 30 unexposed participants.

According to Hoover, researchers will look for biological differences between the two groups. "This is something we couldn't do without recent advances in science," he says.

Animal research has identified persistent epigenetic changes that could be responsible for adverse health impacts. Epigenetic changes are not DNA mutations but rather alterations in how genes turn on and off in the body to accomplish tasks they were designed to do. For example, if genes that protect against breast cancer don't operate properly, then risks for the disease may increase.

"We hope to find a DES signature of epigenetic changes in humans, while also ascertaining if there are differences in hormone concentrations between exposed and unexposed individuals," says Hoover.

He adds that these blood samples may help scientists look for distinguishing differences that could be explained by dose and timing of prenatal DES exposure. "This could be the beginning of unraveling mysteries as to why adverse health impacts vary with-

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JOIN THE CONVERSATION

Facebook For All

With lots going on in the DES community, you can be part of the information flow 24/7. Social media has changed the face of communicating, and DES Action USA is part of it.

Stay on top of information of interest to the DES community and share your thoughts.

Timely — Accurate — Interesting

Check out the DES Action USA Facebook page where we've been talking about:

- The FDA's approval of a new test to "replace" Paps and what it means for DES Daughters
- Adolescent girls prescribed DES in the false belief it would keep them from growing too tall
- The announcement 43 years ago in April that blew the lid off DES
- A Chinese herb under study that may help with Rheumatoid Arthritis, the only autoimmune disorder currently linked to prenatal DES exposure
- The British pardon of the man credited with helping Allies win WWII by breaking German codes but was then convicted of being gay and castrated using DES

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.

We are a caring and supportive group that has become an important benefit of membership in DES Action USA.

Find us on Facebook

twitter

To join send an email to:

DESactionDaughters-subscribe @yahoogroups.com

Once we've checked to be sure you are a DES Action USA member, please join us and participate in the email conversations surrounding the impacts of DES exposure and know your concerns are completely valid. It's empowering knowing you are not alone!

MISSION STATEMENT

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

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What You Need To Know About Paps

There is a difference between having a Pap smear screening and a pelvic exam, although they happen at the same time.

- The Pap itself involves taking a scraping from the cervix (and in the case of DES Daughters a scraping is also taken from the upper vagina) to check under a microscope for abnormal cells.
- A pelvic exam allows your health care provider to view your cervix and vagina to look for abnormal cell development and most importantly for DES Daughters, during the exam the vagina is palpated. Fingertips are used to feel for unusual lumps under the skin, which is where clear cell adenocarcinoma of the vagina develops. It is often felt before it can be seen.

DES experts stress that DES Daughters should have pelvic exams every year, with emphasis on palpating the vagina. No determination has been made as to whether the Pap or HPV test is preferred for DES Daughters.

Complicating the discussion is that DES Daughters may be at higher risk for HPV because many have a wider cervical transformation zone than unexposed women. That's where most of the viral pre-cancerous lesions develop. So it is speculated (but not proven by research) that DES Daughters with their larger transformation zones are more susceptible to HPV.

As screening options evolve, history shows many doctors don't switch immediately to the newest recommendations. What often happens is they wait until respected professional organizations, such as the American College of Obstetricians and Gynecologists, come out with their recommended guidelines—a process that could take some time.

So the option for Pap tests will continue to be on the table even though HPV testing was approved as a primary screening tool. Some doctors may even recommend doing both. DES Daughters should work with their health care providers to decide what is the best course of action for them. But what cannot be overstated is that DES Daughters should be seen for annual pelvic exams no matter what other testing format is selected. DES VOICE

Biomarkers

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in the DES-exposed population."

Individuals asked to give blood for testing will be recruited *only* from participants in the DES Follow-up Study whose health has been monitored for years and who have medical record proof of DES exposure, or the lack of it for the control group. Hoover hopes to have initial data early next year.

Anticipation is high among environmental scientists that a DES biomarker can be identified, because DES is considered the ultimate model for studying the impact of human prenatal exposure to endocrine disruptors.

"We are starting small but with the promise that if something looks interesting, we'll have the possibility of getting resources to do additional work in the future with a larger study," Hoover says.

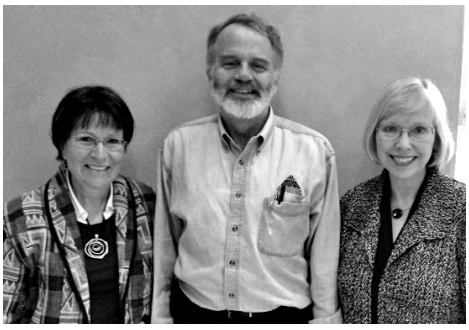
Leader of NCI DES Study Has Career-Long Interest in Hormones and Disease

By Fran Howell

Robert Hoover's passion for the work he does is immediately apparent when you meet him. DES Action USA Program Director Kari Christianson and I had the opportunity to visit with him recently, and we came away upbeat and impressed with the man who heads the National Cancer Institute's DES Follow-up Study.

He walks quickly and brushed off comments that he wasn't wearing a jacket despite the chill of a rainy afternoon. Warm and genuine, Hoover is also a highly respected researcher with a sharp understanding of the dangers hormones pose to health.

Back in 1976 his research published in the *New England Journal of Medicine* (NEJM) was the first population study linking the use of hormone replacement therapy to an increased risk for breast cancer. That was long before general interest in this field of study emerged. Ever since, hormones have been his focus.



Fran Howell, Dr. Robert Hoover, Kari Christianson

During the 1980s, several stud-

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The Consummate Campaigner

Being DES-Exposed Altered The Course Of A Dutch DES Daughter's Life

We reprint, with permission, this article by Jo Shorthouse about a self-described pathological optimist whose DES experiences are helping improve global access to medical care. It first appeared in Scrip Intelligence, November 2013 (www.scripintelligence.com).

Little did Ellen 't Hoen know that when she read a letter to the editor of Dutch newspaper the *Volkskrant* in 1981, the consequences would change her life forever. The letter was from a woman commenting on the recent scandal about using synthetic estrogen in the meat industry, she pointed out that the product controversially used in the farming of livestock had also been used for decades in women to prevent miscarriage.

Confirmation from her mother, that diethylstilbestrol (DES) had been prescribed to her when carrying her daughter, set in motion a series of events that would begin Ms 't Hoen's life's work. From the post-war period to the mid-1970s, DES was used to prevent miscarriage in women. In 1971, DES was shown to cause rare vaginal tumors in girls as young as 14 who had been exposed to this drug *in utero*. Unlike other drugs in pregnancy scandals, such as thalidomide, the main danger to DES Daughters, of which Ms 't Hoen is one, is that the possible effects on the body are not physically manifested on the outside.

Once in contact with her letter-writing fellow DES Daughter, the pair swapped stories of symptoms and suspicions arose as both were told by their physicians that they must be the only ones affected. At this point the media got involved and in no time at all the pair found themselves running an organization for women exposed to DES. This meant Ms 't Hoen's plans of going to law school were postponed. "I was absolutely not interested in getting into healthcare. Nor in becoming a nurse, or a teacher or a babysitter or anything else that was on the list of possible careers for girls. Far from it."

Her DES work with DES Centrum became a full-time job. Those affected in The Netherlands and international action groups, including DES Action USA, came together to exchange information. Of course, the idea of compensation was discussed. This was Ms 't Hoen's first taste of breaking ground in drug policy.

"I've often been involved in initiatives where people have said something is impossible. I remember in the DES days when we started the legal proceedings against pharmaceutical companies, none of the women could point at one particular company that had caused the damage, in terms of product liability, so they couldn't bring suit," she recalls. "So, after studying successful legal cases in the US we decided to sue them all.

"They were collectively responsible for this damage and they had collectively not fulfilled their obligations and been negligent. There was no basis for that in Dutch law. Everyone told us that it was impossible, that it couldn't be done. I don't quit easily, that is not the grounds for not doing something when you feel it is essential to do it. The DES case went all the way to the Dutch Supreme Court and we won the case - opening the door, legally, which then led to establishing the compensation fund."

Working with the DES consumer group was excellent training for the younger Ms 't Hoen. She learnt everything there was to know about one drug, and asked how it could be allowed to happen. When she widened her research and looked at the policy and regulatory environment at the time, she suddenly realized this wasn't a one-drug disaster. "Medications at the time were not properly regulated, the government was not taking responsibility and industry was playing hooky when everything went terribly wrong as a result of systemic difficulties, this wasn't a one-bad-apple picture," she says. Of course, regulatory agencies function very differently today than in the 1940s and 1950s, she adds.

The irony cannot be lost on Ms 't Hoen, that her early work—fighting for individuals that had been unwittingly exposed to drugs—is the exact opposite of her next steps into health policy, campaigning to allow patients access to medicines.

From DES to Doctors Without Borders

In 1990, she left her position as coordinator of the Dutch arm of DES Action and joined Health Action International (HAI) to head the policy and campaigns unit. She worked on promoting the rational use of drugs and the implementation of ratio-

nal drug policy at national level at a time when regulatory agencies were completely closed. She had become involved with a coalition of organizations that involved HAI, Médecins Sans Frontières (MSF), Knowledge Ecology International and later Oxfam, that were working on access to medicines. This was an early experience of coalition in campaigning. "Nobody can achieve things on their own," she says.

Her next move—to MSF's campaign for access to essential medicines—was "quite marvelous" says Ms 't Hoen. "For me it was a huge shift, not so much in the subject matter, but it's quite different to do these kinds of campaigns with a small, not-all-that-well-funded network, as compared to the 800 lb. gorilla that is Médecins Sans Frontières."

The difference in working for MSF came not just with the security of funding, but also with the direct experience in MSF's field projects that could feed into campaigns. In the early days of AIDS drug pricing some innovative projects were conducted throughout the organization, and Ms 't Hoen was involved in intense campaigning that successfully brought about more health-sensitive Intellectual Property (IP) rules at the World Trade Organization (WTO). In 2001, the Doha Declaration was adopted for broader purposes than HIV, but it would never have happened without the HIV crisis, she says.

"A lot of very fundamental change that we've seen in the last decade would not have come about if HIV/AIDS had not been such an enormous disaster. If you just look at what has happened at WTO, the only amendment to a WTO agreement in the whole history of the organization happened because of public health and the HIV crisis driving it," she explains.

Ms 't Hoen also recalls the 2001 South African court case, which saw 39 drug companies sue Nelson Mandela's government for lowering prices on prescription drugs at a time when one in nine South Africans were infected with HIV, and only a few could afford the appropriate drugs. The South African 1997 Medicines Act introduced a legal framework to increase the availability of affordable medicines. Provisions included generic substitution of off-patent medicines, transparent pricing for all medicines and the parallel importation of patented medicines. "Ironically, that ill conceived move [by the pharmaceutical industry] was the best possible contribution pharma could have made to the campaign, because it put the issue of patents and high drug prices at the center of the debate, including at the WTO," she says.

It was the "ticking time bomb" of newer, second-line medicines and fixed-dose combination AIDS drugs, acknowledged and understood by only a few, such as MSF, that sparked a debate in 2002 at the 14th International AIDS Conference in Barcelona.

A small group of people discussed how to get ahead of the disease, how to get away from the "hand-to-hand combat" of access to AIDS medicines, particularly anti-retrovirals. There must be a more systemic and predictable way of doing this, they said, to access innovation in developing countries for people who could not afford high drug prices. Today, there are 26 million people globally who are eligible to receive HIV treatment, according to the World Health Organization (WHO), but only 9.7 million have access, and many take drugs that are no longer in line with WHO guidelines.

A Medicines Patent Pool (MPP) was proposed—whereby companies would share patents through licensing agreements so generic versions of patented drugs could be produced cost effectively. "Sometimes it's these simple notions that can trigger revolutions," says Ms 't Hoen.

It took almost six years for the idea to be put into action. "That's always the problem with these things," she says. "If you try to get ahead of the game it is very difficult to get political support for a problem that isn't big enough yet."

> Confirmation from her mother, that diethylstilbestrol (DES) had been prescribed to her when carrying her daughter, set in motion a series of events that would begin Ms 't Hoen's life's work.

In 2006 the MPP concept finally moved forward and was adopted. Ms 't Hoen founded the MPP in Geneva and served as executive director until 2012. Today, an independent consultant, she still stays involved.

The HIV impact

The devastation of HIV had a galvanizing impact on government organizations to act for positive change, not only financially but on a strategic basis as well, such as the WHO prequalification program. This initiative is "absolutely key for creating a market for quality generics and improving the quality of medicine," says Ms 't Hoen.

Although change has happened as a direct impact of the HIV disaster, the challenge now is to learn lessons from this and apply them to other areas of public health, she explains. "I see some leniency and flexibility for HIV drugs, but if it's something else the door closes. If you look at it from a health perspective it isn't rationale. At MSF we see people living with HIV benefitting from successful treatment then dying of diabetes.

The idea of a MPP (Medicine Patent Pool) received a diverse reaction when the biopharmaceutical industry was approached to voluntarily join.

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YOUR VOICE

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Originally, some WHO member states wanted to make membership compulsory, "but the pharma companies said 'over our dead bodies, but if it is voluntary we'll come to the table'," recalls Ms 't Hoen.

"There was a process of getting to know one another. The nice thing is when you are designing a license agreement it becomes very clear what you want, and very clear where the issues are. Then you can start working through the differences. I think the companies that have entered into direct negotiations with the medicines patent pool look back and think it was a rather good experience," she says. Gilead was the first company to come forward, and this should come as no surprise, she says, with its vast experience in licensing.

Of course some key companies are still not in direct negotiations with the MPP, something that frustrates its founder. "At the end of the day, it's people making decisions. And that's where I can get hopelessly frustrated. You're dealing with people who actually have the ability and the position to make different decisions and they don't," she says.

"Every time you see significant changes happen it is because an individual decided to do things differently and figured out how. If you look at the MPP, you see this is possible." Changes made by the MPP can be swift if all parties are on board. In the case of Gilead, the patent pool managed to obtain licenses for pipeline products, which meant work on technology transfer and licensing to generic companies could begin on the day FDA approval came through for Gilead's products. "It shows that it can be done if people make the decision to do it," she says.

Although companies cannot be forced to join the patent pool, Ms 't Hoen is a "pathological optimist" about the future of the mechanism. "It's just a matter of time because we cannot let a situation develop where access to medicines continues to be a hand-to-hand, case-by-case, drug-by-drug battle where people in need don't get access. That is no longer acceptable when there is a proposal for a collaborative approach on the table. The change within companies to license to the patent pool may seem like a complicated internal process, but that is just used as an excuse for doing nothing."

Now working as a consultant, Ms 't Hoen is also on the advisory board of Universities Allied for Essential Medicines, giving her the chance to train and empower a new generation of potential campaigners.

Although health policy can be taught, perhaps it is having such a personal connection to the subject that makes Ms 't Hoen the best at what she does. "I've worked for change and that's become part of my DNA, maybe that's another consequence of being exposed to DES?" she says with a smile.

Editor's Note: Ellen 't Hoen gave a TED Talk regarding Medicine Patent Pools that can be viewed at: https://www.ted.com/talks/ellen_t_hoen_pool_medical_patents_save_lives

DES VOICE

Leader of NCI DES Study

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ies of human DES exposure were underway simultaneously around the country. Enthusiasm for the work was flagging, as one by one research teams were losing funding. But Hoover recognized the value of keeping DES research going.

Here were groups of DES-exposed individuals with medical record proof of exposure, including both dose and timing. The studies also included matched control groups of unexposed individuals with proof of no prenatal DES exposure. The tragedy of the DES experience had yielded science a huge gift, and Hoover understood its importance.

Through his efforts within the National Institutes of Health, along with those of others including DES Action USA, both Congresswoman Louise Slaughter and Senator Tom Harkin were convinced to sponsor legislation that in 1992 succeeded in giving the National Cancer Institute a mandate to continue DES research.

Once Hoover was able to bring the studies "in house," he reassembled the disparate projects into the DES Follow-up Study that continues to this day.

Scientifically Different Approach

Most research studies start with a hypothesis to prove or disprove. But DES science started out differently. Aside from the known link between prenatal exposure and a rare form of vaginal cancer, there wasn't anything else to go on. Says Hoover, "We went out on a limb—we didn't know what we'd find. Of course, we hoped we wouldn't identify any further adverse impacts. But if they were there, we needed to know about them."

Through the years 12 medical conditions for DES Daughters have been linked to their exposure, thanks to the work done by Hoover and his research colleagues. His landmark article in the October 2011 NEJM helped reach doctors with this important information.

DES studies have held Hoover's attention through the years. He remains positive and enthusiastic about learning not only *how* endocrine disruptors, such as DES, affect disease, but also the biologic causes of *why* they work in our bodies the way they do.

Hoover is particularly excited about the search for a DES biomarker. "We are part of a revolution in science that combines epidemiological and biological research at a molecular level. Results will help us all make smarter decisions regarding hormonal exposures. The work on DES exposure is leading the way!"

DES VOICE

DES: A Cautionary Tale

Breast Cancer Fund again gives us a most thorough review of scientific studies related to the endocrine disruptor BPA (Bisphenol A). Their publication, *Disrupted Development: The Dangers of Prenatal BPA Exposure*, provides consumer-friendly information about the studies. Best of all, this report guides us on how we can avoid BPA in our diet and how to demand legislative and industry change in how our food is packaged.

DES and BPA are linked through Sir Charles Dodds. He wanted to develop estrogenic drugs and recognized the estrogenic properties of BPA, which had been developed 40 years previously. Although he developed the more potent estrogen DES in 1938, BPA was not forgotten. It was subsequently used in the development of plastics and epoxy resins and is a component in food packaging today.

Sometimes, those of us who are DES-exposed forget how important the entire body of DES research is to understanding endocrine disruptors in our environment and food chain. Breast Cancer Fund's "Disrupted Development" reminds us that DES-exposed individuals are not forgotten and much is still being learned from our DES experience. This cautionary tale has not ended…. DES VOICE

The drug diethylstilbestrol (DES) provides a striking and tragic example of the effects of prenatal exposures to chemicals that disrupt our hormones. DES was initially synthesized by a research team in London that had been searching for compounds that could be used for estrogen replacement during menopause, then referred to as "deficiency disease." DES was approved by the FDA in 1941 to prevent miscarriages. It was prescribed to pregnant women for this purpose until 1971.

Early systematic studies failed to find evidence that DES was effective at preventing miscarriages, but it continued to be prescribed to pregnant women. The wide use of DES created an accidental experiment that led to 5–10 million pregnant women—and the children born from those pregnancies—being exposed to this synthetic estrogen.

From 1966 to 1969, doctors at the Vincent Memorial Hospital in Boston (now part of Massachusetts General) noted a pattern of rare vaginal cancers in young women. These cancers were rare even in women over 50, and the hospital had never seen a single case of that specific type of cancer in younger women prior to 1966. The doctors conducted a study to determine similarities among the women, and found that the common thread was their mothers' use of DES during their pregnancies. The doctors published a paper reporting their findings in the *New England Journal of Medicine* in 1971, after which DES prescriptions dropped significantly.

Since 1971, further research has linked prenatal DES exposure to a nearly two-fold increase in breast cancer among women over 40, and even higher rates among women over 50. Women who were presumed to have the highest exposures to DES (estimated based upon how much their vaginal cells were altered) had a higher risk of breast cancer.

The story of DES provides a cautionary tale about prenatal exposures to chemicals that can mimic the body's own hormones. BPA is one such compound—In fact, BPA was even considered as an estrogen replacement by the same London laboratory that first created DES. As the DES story underscores, it can take decades to recognize the long-term health effects of early exposures to hormone-disrupting compounds in the general population, making it even more critical that we act on early warnings of harm.

Reprinted with permission from Breast Cancer Fund. The entire publication, *Disrupted Development: The Dangers of Prenatal BPA Exposure*, is available for free download at www.breastcancerfund.org

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A Healthy Baby Girl

Now Available For Digital Download: https://itunes.apple.com/us/movie/a-healthy-babygirl/id847565736

Watch how DES tears at the fabric of a family and strengthens the resolve of a DES Daughter. Emotional and raw—and worth a second look!

Maybe you saw this movie when released in 1997, or have heard about it since then. It's the most talked about DES film and has done more than any other to capture the personal emotional traumas created by the DES tragedy.

Difficult to get for several years, the documentary can now be easily accessed digitally and viewed again, or seen for the first time.

At age 25 and already a filmmaker, Judith Helfand used a video camera and documented the five years of her life following an emergency hysterectomy for DES-related

cervical cancer. To their huge credit her brave family let the camera roll during this wrenching time.

Helfand worked through her overwhelming anger, depression and hurt while her mother wrestled with the added emotion of guilt. Seeing the shattered pieces of their mother/daughter relationship ultimately restored is powerful in light of how the DES experience strained so many families. DES exposure is much more than a medical issue alone.

About her mom, Helfand says, "I can say with love, respect and the utmost certainty that via this whole experience—from caring for me when I was ill, to letting me film our innermost pain and loss, to laughing with me in the face of heedless corporate power, my mother taught me all I need to know about parenting, motherhood and continuity."

The movie has increased poignancy because Helfand's mom died in September. But then suddenly and joyfully in April the terrible loss was mitigated somewhat when Helfand was able to adopt her own healthy baby girl. We send our best and happiest wishes to both of them! DES VOICE