



Letter from the Director

Dear Child Health and Development Studies (CHDS) Participants,

Happy Fall 2011! It has been another busy year for us at the CHDS, and I am excited to update you on study progress and the latest news from our office. In our last newsletter, we wrote about the start of the Disparities Study and the Three Generations Study, now both well under way. Many of you have likely already heard from us through these studies, and we are grateful for your continued involvement. I'm also happy to announce the creation of our first Participant Advisory Council, a group of CHDS participants that will help guide future research. It was lovely meeting with our participants face to face, and I look forward to the meetings we will have over the next several years.

We truly enjoy hearing from CHDS families and look forward to another year of being in touch with you through our current studies and this newsletter. Thanks for your past and future participation in the CHDS—you're making a difference!

Barbara Cohn, PhD, *Principal Investigator*

CHDS Introduces Participant Advisory Council

The CHDS launched its first Participant Advisory Council (PAC) in April of this year. The PAC is a dynamic group of 19 CHDS mothers, sons and daughters that will assist CHDS staff in the research process through a new model of participant engagement called participatory research.

Participatory research is a growing trend in health and medicine. In this model of research, community members work side by side with scientists to plan research studies. Rather than recruiting individuals from the community at large, CHDS staff invited CHDS participants who live in the Bay Area to help

guide research on their own data. The PAC will help CHDS researchers identify health topics that are important to study members, develop new strategies to increase participation in CHDS studies, address ethical issues like appropriate consent procedures and determine the best ways to disseminate study results.

The PAC is funded until 2014 by the National Institute of Environmental Health Sciences and the National Cancer Institute. During this time, the PAC will hold 15 meetings. The PAC's goal is to be self-sustaining and to continue its partnership with the CHDS after the funding period ends.



Dr. Cohn speaks to the PAC at a meeting last April.

We are thrilled to get to know the PAC members, hear about their life experiences and share how the CHDS research process works. These advisors will help enhance ongoing engagement in the CHDS for all participants.

CHDS RESEARCH HIGHLIGHTS

A new study published this year by CHDS researchers indicates for the first time that a daughter's exposure in her mother's uterus to polychlorinated biphenyls (PCBs) can affect how long it takes the daughter to become pregnant years later.

The study, which appeared in the April issue of the journal *Reproductive Toxicology*, found "time to pregnancy" (TTP) was longer and thus more difficult for daughters who had been exposed to certain forms of these man-made industrial chemicals.

The new study analyzed the PCBs in blood taken from CHDS mothers shortly after delivering their daughters. The study asked 289 of the daughters — all about 30 years old — how long they had tried to become pregnant. Women who ultimately could not conceive had been exposed in the womb to higher

levels of the PCB compounds that were linked to longer periods of time without a pregnancy.

PCBs were widely used in electrical equipment such as transformers and capacitors as well as in paints, plasticizers, pesticides and adhesives from 1929 until 1977. The U.S. banned the manufacture and use of this class of organic chemicals in the 1970s because of the chemicals' toxicity and link to cancer and other serious health effects. However, PCBs have been distributed in the soil, water and food chain virtually everywhere in the world and persist because they degrade slowly. Though banned, the study is relevant because PCBs share structural similarities with chemicals currently still in use, such as compounds used in flame-retardant materials.

The authors caution that the study does not provide a conclusive



explanation for the difference in TTP. It is unknown whether the PCB exposure was the sole cause or whether other environmental exposures also contributed. The results could also be explained by underlying health problems of the daughters or her partner, other factors, or by chance.

Future studies will examine other possible health-related consequences of PCB exposure.

Cohn, B.A., et al. Polychlorinated biphenyl (PCB) exposure in mothers and time to pregnancy in daughters. *Reproductive Toxicology*, 2011. 31(3): p. 290–296.

Dr. Cohn Serves as Co-Chair of the NICHD Vision Process

Earlier this year, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) began developing its "Scientific Vision" for the next decade. The Scientific Vision will identify the most promising scientific opportunities within the NICHD's focus areas: reproductive health, pregnancy and child health.

Dr. Barbara Cohn, who directs the CHDS, was invited to serve as co-chair of the Scientific Vision Workshop on the Environment, one of nine priority topics outlined by the NICHD. As part of this role, she coordinated a panel of experts to identify several challenges and opportunities in research on environmental effects on human health.

Opportunities brought out in the workshop include the need to: 1) increase research on new chemicals that have not been studied for long-term safety, and 2) continue the gains in discovering how the timing of chemical exposure in a person's life (known as "windows of susceptibility") affects health outcomes. To study delayed effects of environmental exposures, the scientists recommended taking advantage of long-term studies like the CHDS and naturally occurring experiments like the nuclear disaster in Japan this past March.

Findings from all nine workshops will be presented and packaged into a vision statement in December.

The NICHD is a branch of the National Institutes of Health, the government agency responsible for conducting medical and health research.

Dr. Cohn recently discussed environmental exposures and windows of susceptibility for developing breast cancer in a web forum at the Public Health Institute. You can listen to the recording online at: www.dialogue4health.org/webforums/7_7_11.html.

We asked the PAC...

What's your first memory of the CHDS?

- ▶ Being asked to enroll in a study with my newborn baby girl.
—CHDS mom
- ▶ Getting a toy when I would go in for the research visit as a child.
—CHDS son
- ▶ Being invited by the CHDS earlier this year to participate in an interview and home visit.
—CHDS son

Why did you choose to participate on the CHDS Participant Advisory Council?

- ▶ I want to help future generations be the best they can be.
—CHDS mom
- ▶ I felt I would learn a lot about breast cancer and the 3Gs study.
—CHDS daughter

- ▶ I'm very interested in public policy and public health, and want to contribute my perspective as one of the original subjects.
—CHDS son

What does it mean to you to be a part of the CHDS and the PAC?

- ▶ I am honored to be a part of it. I have already learned so much.
—CHDS daughter
- ▶ It is very interesting and the enthusiasm of the staff is refreshing. It makes me feel like I'm part of something special.
—CHDS son

What would you say to someone who is thinking about participating in a CHDS research study?

- ▶ Anything we can do, no matter how small it seems, can make a big difference in the future of all.
—CHDS son



Dr. Barbara Cohn talks with a PAC member at the July meeting.

- ▶ So much information can be gained with very little effort on your part. It feels great to be on the cutting edge of knowledge.
—CHDS mom
- ▶ The information collected will be invaluable to people, possibly even in ways no one can imagine.
—CHDS daughter
- ▶ Get involved! —CHDS son

Over the past year, we have been contacting participants and conducting interviews and home visits. We have made excellent progress in reaching our recruitment goals for the two studies we described in our last newsletter: the Disparities Study and the Three Generations Study (3Gs).

In the Disparities Study, 382 CHDS participants have enrolled. This study aims to recruit 300 men

and 300 women for an interview and home visit. Researchers using data collected from this study will examine inequalities in health outcomes.

The 3Gs Study has enrolled 1,289 CHDS participants in the telephone interview. Later this year, 1,000 women and their daughters will be invited to participate in a home visit. 3Gs will continue into 2014 and recruit a total of 4,000 CHDS daughters to examine how diseases like breast cancer may pass from one generation to the

next or be caused by environmental exposures.

In 2012, the CHDS will launch a companion study called Pedigree. About 400 3Gs participants will be asked to provide their most recent mammogram readings. Like 3Gs, researchers will use data from Pedigree to study the potential environmental causes of breast cancer.

Think you are eligible but have not been contacted? Call us at 510-649-6390 or toll-free at 1-877-482-0264.

CHDS STUDY UPDATES



chds

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The CHDS Difference

The CHDS began over 50 years ago. We have followed up with thousands of families since they first participated, creating a rich database on health across the lifespan. Because of this foundation, the CHDS is a scientific treasure, allowing important questions about health to be answered without waiting 50 years. Through these studies, CHDS scientists work to uncover ways to improve health and prevent disease early in life. CHDS scientists study child development, fertility, cancer, mental health, and other health issues.

Because of the CHDS, doctors know:

- Which medicines pregnant women can take safely to reduce nausea and which medications for mental health disorders and fluid retention may be harmful or require more testing
- Smoking during pregnancy and exposure to second-hand smoke can be harmful to an unborn child
- How to assess normal gains in weight and height for children



CHDS Kids – 1960s

- Why some men and women are more at risk for infertility
- Protective factors for aging men and women that may help prevent cancer, heart disease, asthma and diabetes