



CHILDHOOD AUTISM RISKS FROM GENETICS AND THE ENVIRONMENT

Issue 1

CHARGE Study Newsletter

February 2003

WELCOME

As Principal Investigator of the CHARGE Study, I am pleased to announce the launching of the first large epidemiologic study to examine environmental factors as causes of autism. We have named it the CHARGE Study (**C**hildhood **A**utism **R**isks from **G**enetics and the **E**nvironment). In this first newsletter, we introduce the study investigators and staff, describe the CHARGE Study, and hear from a parent on the Community Advisory Council (CAC). This quarterly newsletter will keep you abreast of our progress in recruitment and the scientific discoveries from this study, and provide dates and times of upcoming activities and events that may be of interest to you.

The CHARGE study is a collaborative effort involving the University of California Davis Center for Children's Environmental Health and the M.I.N.D. (Medical Investigations of Neurodevelopmental Disorders) Institute, the University of California Los Angeles, and the Kaiser Permanente Division of Research. We are interested in how environmental exposures might increase risk of autism, and in how these environmental factors may interact with genetic susceptibility to modify risk.

Little is known about what causes autism or developmental delay. By studying children with different patterns of development, we hope to learn more.

Irva Hertz-Picciotto, Ph.D. Principal Investigator

A PARENT'S VIEW

It was a pleasure to meet the study team at the Community Advisory Council meetings. I was impressed by the diversity among the team members as well as their expertise. I completely support the direction and the approach taken by the CHARGE study. As a parent of a child with

autism, I appreciate being involved in the planning process with a project of this magnitude. I hope we can increase the awareness of the study in the community by providing brochures and other promotional materials. I feel that the best way to maximize participation from the potentially eligible groups of children will be to widely publicize the study. I'm hopeful that informational materials will be developed that keep the different groups in mind because every family has specific interests and concerns about genetics and the environment. Most of all, I'm excited because finally a study is being done that will answer questions we parents have been asking: Why did my child become autistic?

Tom Hayes, Parent & CAC member

WHO WILL BE IN THE CHARGE STUDY?

Over the next 3½ years, we plan to recruit 700 families with autistic children, 600 families with developmentally delayed or mentally retarded children, and 700 families with typically developing children. Eligible children are those: aged 24 to 54 months; living with at least one biologic parent; born and currently living in the study areas (see Regional Centers below); and whose parents speak English or Spanish.

If your child was recently diagnosed with autism, developmental delay or mental retardation at one of our collaborating Regional Centers, your family may be eligible to participate. Please call our toll free number: 1-866-550-5027 or talk with your Regional Center representative.

WHAT WILL PARENTS BE ASKED TO DO?

- Give permission for us to review their child's Regional Center charts (for children with autism, mental retardation or developmental delay).
- Bring their child to UC Davis or UCLA for a clinical assessment, which will include an autism evaluation, a medical examination and a series of tests of development.

- Be interviewed about events, activities and exposures during the pregnancy and early childhood.
- Give specimens of blood, cheek cells, hair, and urine from the child, his or her siblings, and the parents.
- Give us permission to obtain and review prenatal, labor and delivery, and pediatric medical records.
- Give us permission to obtain blood spots that the State of California collected when the child was born.

GETTING STARTED

In the past year, CHARGE has hired and trained staff, obtained approval from three Institutional Review Boards for the protection of human subjects, and developed collaborative relationships with the California Department of Developmental Services (DDS) (many thanks to Mary Lu Hickman, Ron Huff, and Cliff Allenby!!) and with six Regional Centers, who will serve as the initial contact points for recruitment of autistic, mentally retarded, or developmentally delayed children. We also have prepared protocols for the identification and selection of typically developing children for the study.

The following Regional Centers are participating in the CHARGE Study: in the Los Angeles area, Lanterman, Westside, and East Los Angeles; in the northern California, North Bay, Valley Mountain, and Alta. We are very grateful to the directors and staff of these Regional Centers, who have graciously made room in their busy schedules to support this research effort!

COMMUNITY ADVISORY COUNCIL

Also in the past year, we have convened two meetings (April and November of 2002) of the Community Advisory Council. This group consists of parents, service providers, representatives from DDS and the Regional Centers, and other researchers. These sessions have been extremely rewarding, and have generated many helpful ideas that will contribute to the success of the study.

COMMUNITY ADVISORY COUNCIL MEMBERS

Kathleen Berry (Parent)	Linda Copeland (Physician)
Thomas Hayes (Parent)	Howard Cohen (Provider)
Portia Iversen (Parent)	Judith Grether (Researcher)
Karlin Merwin (Parent)	Randi Hagerman (M.I.N.D.)
Matt Moran (Parent)	Ron Huff (DDS)
Marianne Toedtman (Parent)	Ricki Robinson (Provider)
Nila Rogosin (Researcher)	Sally Ozonoff (M.I.N.D.)
Renee Wachtel (Physician)	Rick Rollens (Parent)
Mary Lu Hickman (DDS, retired)	

THE CENTER FOR CHILDREN'S ENVIRONMENTAL HEALTH (CCEH)

The CHARGE Study is one component of the UC Davis Center for Children's Environmental Hhealth (CCEH). Under the overall direction of Isaac Pessah, Ph.D., CCEH Director, a multidisciplinary team of researchers are pursuing numerous investigations of autism, focusing on genetics, chemical exposures, cell signaling, animal models, and metabolism.



The Center for Children's Environmental Health (Left to Right) Isaac Pessah and Melissa Rose

WHO'S IN CHARGE

Northern California Team

The University of California, Davis is home base for the CHARGE Study. Dr. Irva Hertz-Picciotto (Principal Investigator), Dr. Robin Hansen and Dr. Lisa Croen will combine their medical and epidemiological expertise. They will be assisted by Dr. Gary Hughes, Project Manager, and a diverse team including statistician, research assistant, project coordinator, medical record abstractor, interviewer, web programmer, and statistical programmer. Together, they will address the

complex clinical, developmental and environmental aspects of the participant, recruitment, data collection, and statistical analysis for this study.



Northern California Team: Front Row (Left to Right) Irva Hertz-Piccioletto, Cynthia Contreras, **Second Row:** Keith Jose, Lisa Croen, Olivia Kasirye, Amy Harley, Toni Hall **Back Row:** Gary Hughes, Yan Liu **Tree:** Jake Wegelin **Not pictured:** Robin Hansen and Kris Herman

WHO'S IN CHARGE

Southern California Team

Led by Dr. Marian Sigman, the Southern California CHARGE staff is also assembled and ready to go



Southern California Team: Front Row (Left to Right) Front Row: Liz Lizaola, Caitlyn Beck **Back Row:** Michael Bono, Sara Clavell, Cindy Huang, Angela French, Marian Sigman

into the field. Dr. Michael Bono, Project Manager, Sarah Clavell, Laura Espana and Liz Lizaola have

many years experience in conducting studies of young children with autism and are eager to CHARGE forward. We welcome Angela French, our medical abstractor, as the newest member of the UCLA team.

REGIONAL CENTERS ARE KEY TO THE SUCCESS OF THE STUDY

The CHARGE Study has begun recruitment efforts! Families meeting study criteria are being identified and contacted by staff at the 6 collaborating Regional Centers. Regional Center staffs have worked hard to develop an effective recruitment process. Their cooperation and collaboration with the CHARGE Study is essential to the success of the project, and very much appreciated.

THANK YOU REGIONAL CENTER COLLABORATORS!!

Alta Regional Center
Joanne Tremelling

Eastern Los Angeles Regional Center
Felipe Hernandez

Lanterman Regional Center
Deborah Murphy

North Bay Regional Center
David Katayama

Valley Mountain Regional Center
Howard Cohen

Westside Regional Center
Soryl Markowitz

WHO'S FUNDING CHARGE?

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