



## Database Helps Diagnose and Prevent Fetal Alcohol Spectrum Disorders Worldwide

by Kate Forster

Since the discovery of Fetal Alcohol Syndrome (FAS) at the University of Washington in 1968, the CHDD has contributed a great deal to advance research in the field and provide resources in order to diagnose, treat, and prevent this condition. Examples of such resources include the CHDD Fetal Alcohol Spectrum Disorders (FASD) clinic and the Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) database. Susan Astley, Ph.D., professor of epidemiology and pediatrics and CHDD research affiliate, created this database when she first helped open the clinic in 1993. At the time, it was a standard practice to discard or shred most of the patients' information at the end of the day. Trained as an epidemiologist, Astley understood the importance of saving this data, and with the approval of the Human Subjects Review Board, she began collecting patient data from the clinic and entering it into a database from the day it opened. To date, the FASD clinic has evaluated nearly 3,000 patients, and the database contains over 2,000 fields of information on each patient. It is also supported by over one million pages of scanned records. The FAS DPN database has since become one of the world's largest and most comprehensive databases on FASD.



*Susan Astley maintains the Fetal Alcohol Syndrome Diagnostic and Prevention Network database.*

### Creating an evidence-based FASD diagnostic system

In addition to creating a patient database, Astley recognized the need to improve the way FASD was diagnosed. "When the clinic first opened," she said, "there was no precise method for diagnosing FASD. The diagnosis was made using a gestalt approach—that is, 'I know it when I see it,' which led to highly variable and inaccurate diagnoses." To Astley, it quickly became clear that this could be improved. She used the information she recorded in the database to develop a diagnostic system for FASD. She began by addressing the most obvious part of the diagnosis—the face. She took photographs of every patient that came through the clinic, measured their facial features, and then performed a statistical analysis to identify which facial features best distinguished the individuals with FAS from those without it. The result was a set of facial features that were found to be caused only by prenatal alcohol exposure: small eyes, smooth philtrum (the space between the nose and upper lip), and a thin upper lip. The more severe the facial features, the more severe the effects associated with FASD.

Once the facial features were identified, Astley used the database to better define the two remaining aspects of FASD—growth deficiency and brain abnormalities. From this, she established rigorous

diagnostic criteria for FASD and worked to ensure its scientific accuracy. “If you create a diagnostic system,” she said, “it’s incumbent upon you to validate its performance. To show how you’ve come to your conclusion, you need to have the data to support its accuracy. I spent most of my career using the database to do validation research and establish an evidence base for the diagnostic system.” Astley’s research resulted in the development of the FASD 4-Digit Diagnostic Code, the Lip-Philtrum Guides, and the FAS Facial Photographic Analysis software. These tools are now used worldwide to diagnose FASD.

Not only has the database been used to develop tools to diagnose FASD, it has also been used as a guide in treating and preventing it. For 10 years, the FASD clinic partnered with King County to determine the incidence of FASD in children in the foster care system—who are at greater risk of having been exposed to alcohol in utero. Photographs were taken of the children’s faces, and Astley compared their facial features to the facial characteristics of FASD, as determined by the FAS Facial Photographic Analysis software. Those who had the facial characteristics of FASD were brought into the clinic for a diagnostic evaluation. The screening confirmed that one out of 100 children in foster care had full FAS, ten times the prevalence in the general population. Those who were diagnosed were then eligible for the Families Moving Forward Program, an intervention developed at the University of Washington by CHDD research affiliate, Heather Carmichael Olson, Ph.D., that provides individualized services for families raising children diagnosed with FASD. “While there is no cure, early intervention helps children with FASD reach their full potential,” said Astley.

By working to identify the birth mothers of children who have already been diagnosed, Astley and her clinic also strive to prevent future cases of FASD. “While she’s typically no longer the guardian of the child,” said Astley, “she’s at risk of bearing more children who are exposed to and damaged by alcohol.” Those identified are referred to the Parent-Child Assistance Program (PCAP), a state-wide intervention program developed at the University of Washington by CHDD research affiliate, Therese Grant, Ph.D. The PCAP works in partnership with the FASD clinic, providing treatment for women who abuse alcohol while pregnant and offering services in family planning.

Astley’s work contributed to a significant decrease in the prevalence of FAS and maternal drinking during the 10 years she worked with King County. She attributes this success to being able to more accurately diagnose FASD. “An accurate diagnosis allows you to correctly count the incidents of FASD and determine how big the problem is,” she said. “From a prevention standpoint, you have to be able to accurately diagnose it before you can count it. Otherwise, you don’t know whether or not your interventions are working because you cannot determine whether the count is going down. So you can begin to see that everything revolves around an accurate diagnosis—whether it’s prevention, surveillance, screening, or intervention—and it’s the database that has provided the means for this.”

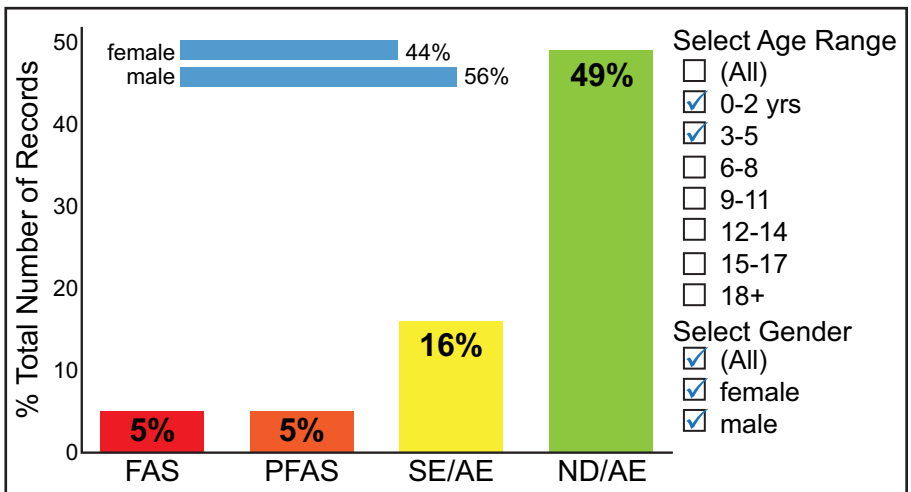
### **Valuable research tool**

The FAS DPN database also serves as a valuable research tool. Astley and members of her team have used the dataset to publish numerous papers on FASD screening, diagnosis, intervention, and prevention. The dataset also serves as a patient registry for researchers, and it has been identified as such by the Human Subjects Review Board. “The database allows us the flexibility of contacting individuals who fit specific criteria for particular studies. For example, a study might want to focus specifically on 3–5 year-olds or on those who have certain symptoms,” she said. “We have a formal way of contacting our patients and asking them if they’re interested in the latest research project that they’re potentially eligible for.” In 2015, the FAS DPN was recognized by the American Association of Pediatrics as a national and international leader in FASD diagnostic, prevention, and intervention practices.

## Making the data broadly available

The next step Astley wants to take is to make the dataset available to anyone who wants it by using the web-based visualization platform, Tableau, which the University of Washington has made available to all its faculty and staff. Tableau lets researchers create and post their data in the form of dashboards that users can visually interact with. Users specify the information they need to create pie charts, bar charts, graphs, and the like. When the FAS DPN dataset is made available through Tableau, users from all over the world will be able to visually interact with it. “Instead of my publishing papers based on the questions I personally think are important, this will give people around the world access to this dataset via the web and the ability to interact with and manipulate the data in ways that they think are important, and that really opens things up.” Astley is currently building the Tableau dashboards that will give users worldwide access to one of the world’s largest FASD datasets, the FAS DPN database.

*With Tableau, users can easily generate graphics by filtering different combinations of information. In this example, when a user selects 0–5 years of age at the time of diagnosis and both genders, they can see that the clinic sees more males (56%) than females (44%). They can also see the distribution of FASD diagnoses across this group.*



CHDD is an interdisciplinary center dedicated to the prevention and amelioration of developmental disabilities through research, training, clinical service, and community outreach. CHDD includes the University Center of Excellence in Developmental Disabilities and the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center.

### CHDD Outlook

Center on Human Development and Disability, University of Washington, Box 357920, Seattle, Washington 98195-7920

© 2016 Center on Human Development and Disability, University of Washington

For more information please contact us at [chdd@uw.edu](mailto:chdd@uw.edu)