VII. STANDING COMMITTEES

A. Academic and Student Affairs Committee

<u>Faculty Presentation: Fetal Alcohol Spectrum Disorders (FASD) – From Discovery to Prevention at the University of Washington</u>

INFORMATION ONLY

Susan J. Astley, Ph.D.
Professor of Epidemiology, School of Public Health
Professor of Pediatrics, School of Medicine
Director, WA State Fetal Alcohol Syndrome Diagnostic
& Prevention Network (FAS DPN)
Vice Chair Faculty Senate
University of Washington
Seattle WA

Dr. Astley received her B.S. in Biology, her M.S. in Radiology and Physiology, and her Ph.D. in Epidemiology. She is a member of the American Association of Public Health and the Research Society on Alcoholism and is a Research Affiliate at the Center on Human Development and Disability at the University of Washington.

Dr. Astley has conducted laboratory, clinical, and public health research in the field of FASD since 1981. Fetal Alcohol Syndrome (FAS) is a permanent birth defect syndrome caused by maternal alcohol consumption during pregnancy. Current work has been in the development and implementation of diagnostic, screening, surveillance, and prevention tools and programs in FASD, which is FAS-caused brain damage without the physical features. This work includes the development of the FASD 4-Digit Diagnostic Code and FAS Facial Photographic Analysis Software; establishment of the WA State FAS Diagnostic and Prevention Network of clinics and Foster Care FAS Screening Program; and establishment of the FASD diagnostic training program and Online Course. She and her colleagues have recently published a comprehensive study of the diagnostic utility of MRI, MR-spectroscopy and functional MRI for FASD. Two additional focal publications include: 1) Washington State's success in preventing FAS through reduction of maternal alcohol use during pregnancy, and 2) Clinical profiles of 1,400 patients with prenatal alcohol exposure.

She has received funding from NIAAA, CDC, SAMHSA, the National March of Dimes, the Alcohol and Drug Abuse Institute, the Royalty Research Foundation, Chavez Memorial Fund, and the WA State Legislature.

VII.   STANDING COMMITTEES

A.   Academic and Student Affairs Committee

Faculty Presentation: Fetal Alcohol Spectrum Disorders (FASD) – From
Discovery to Prevention at the University of Washington (continued p. 2)

John C. Thorne, Ph.D.,
Instructor and Clinical Supervisor
Clinical Training Unit, Center on Human Development and
Disability
Department of Speech and Hearing Sciences
University of Washington
Seattle, WA

Dr. Thorne received his B.A. in English, his M.A. in Curriculum & Instruction,
his M.S. in Communication Disorders, and his Ph.D. in Speech and Hearing
Sciences. He is a member of the American Speech-Language Hearing
Association and is a clinical supervisor at the Center on Human Development and
Disability at the University of Washington and Instructor in the University of
Washington Department of Speech and Hearing Sciences. Dr. Thorne completed
his Ph.D. at the University of Washington in 2010 with original research on the
integrative language abilities of children with Fetal Alcohol Spectrum Disorders
(FASD). He is the author or co-author on several book chapters on the subject.
His current research involves the development and validation of clinical tools for
measuring integrative language abilities that will support clinical decision making
and intervention planning for school-aged children with developmental
disabilities, including those with FASD. This includes the development of two
language sampling and analysis systems, *Tallying Reference Errors in Narratives*,
and the *Semantic Elaboration Coding System* (more information including links to
recent peer-reviewed research articles on these systems is available at
http://johncthorne.wordpress.com/).

Dr. Thorne has received funding from through the University of Washington
Leadership Education in Neurodevelopmental and Related Disabilities (LEND;
supported by the Maternal and Child Health Bureau of the Health Resources and
Services Administration, U.S. Department of Health and Human Services), as
well as the University of Washington *Research Training in Speech and Hearing
Sciences* (an interdisciplinary training grant supported by the National Institutes
of Health).

VII.   STANDING COMMITTEES

A.   Academic and Student Affairs Committee

Faculty Presentation: Fetal Alcohol Spectrum Disorders (FASD) – From
Discovery to Prevention at the University of Washington (continued p. 3)

Susan Astley and John Thorne will speak about work at the University of
Washington on Fetal Alcohol Syndrome. FAS is characterized by growth
deficiency, a unique cluster of minor facial anomalies, and brain
damage/dysfunction. The prevalence of FAS in the general population is 1 to 3
per 1,000 live births. This is roughly equivalent to the prevalence of Down
Syndrome. The prevalence of FAS in King County foster care is ten-fold greater
(1/100). FAS is only the tip of the iceberg. For every child with FAS, there are
5-10 children with FASD (brain damage without the physical features). FASD is
the leading known cause of developmental disability and is entirely preventable.

The University of Washington is the world leader in the field of FASD. FASD
was first discovered at the UW in 1968. Programs and policies established
through the seamless collaboration between the University, the State legislature,
and State agencies have led to the successful prevention of FASD. It is rare to
witness a medical condition advance from discovery to prevention in one's
lifetime. This rare public health success story is a beautiful illustration of the
unlimited potential and contribution of a first-class academic/research/medical
institution.

This story is best told through the accomplishments of three UW students. In
1968, a student of medicine (Christy Ulleland, MD) discovered FASD. In 1995, a
student of law (Andrea McNamara, JD) wrote Senate Bill 5688 to establish the
first ever statewide network of diagnostic clinics (the WA State FAS Diagnostic
& Prevention Network). This, in turn, would pave the way for a student of public
health (Susan Astley, PhD) to develop diagnostic, screening, and surveillance
tools that would lead to the successful prevention of FASD. The UW FAS DPN
program has trained thousands of clinicians worldwide through web-based
dissemination of its diagnostic tools, facial recognition software, and Online
training course. The future of the FAS DPN lies in the hands of the next
generation of UW students who are now joining the faculty.

Attachment: FAS Diagnostic & Prevention Network

FAS DPN
Center on Human Development & Disability
University of Washington, Seattle WA

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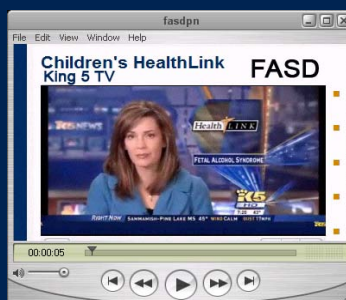Search

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Directions

NEW

- (2004) 4-Digit Diagnostic Code
- (2006) 4-Digit Code vs Revised IOM
- FAS Prevention: Evidence of Success
- FASD Diagnostic Outcomes by Region
- 4-Digit Code Online Course
- Growth Charts
- Palpebral fissure length measurement accuracy.
- Template for FASD Medical Summary Note
- Animated Facial Photography and Measurement Instruction
- FASD-4-Digit Short Form (1-page fillable form)
- (2009) FASD MRI-MRS-fMRI-Psychological Study Outcome
- (2009) Graphic Profile of WA FAS DPN Patients with FASD
- (2010) Profile of 1,400 WA FAS DPN Patients with FASD
- Video introduction to FAS Facial Photo Analysis Software

Profile of 1,400 Patients with FASD
Webcast, Toronto 2010

FAS DPN | FAS Diagnostic & Prevention Network

What is the FAS DPN?

The Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FAS DPN) is a network of four WA State community-based interdisciplinary FASD diagnostic clinics linked by the core clinical/research/training clinic at the Center on Human Development and Disability at the University of Washington in Seattle, WA. Susan J. Astley, Ph.D., Professor of Epidemiology/Pediatrics, is the Director of the FAS DPN. The network was established in 1993 through Washington State Senate Bill 5688 and support from the CDC, March of Dimes, Chavez Memorial Fund, and WA State Department of Social and Health Services.

Each clinic in the network uses the same interdisciplinary approach to diagnosis and the same systematic diagnostic method-the 4-Digit Diagnostic Code. The mission of the FAS DPN is primary and secondary prevention of FAS through screening, diagnosis, intervention, training, education, and research. The WA State FAS DPN began diagnosing patients in 1993 and has diagnosed over 2,000 patients to date.

The mission of the FAS DPN is FASD prevention through FASD screening, diagnosis, intervention, research, and training.

The WA State FAS DPN has expanded both nationally and internationally through the training of interdisciplinary teams. Several hundred interdisciplinary teams have been trained around the world. Major accomplishments of the FAS DPN include:

Screening

- Creation of a computerized FAS Facial Photographic Screening Tool.
- Ten-year, population-based FAS screening in foster care confirming, 1 out of every 100 children in WA foster care has FAS.
- Juvenile Justice FASD Screening/Diagnostic Initiative.

Diagnosis

- Creation of the FASD 4-Digit Diagnostic Code.
- Creation of the FAS Facial Photographic Analysis software.
- Creation of the interdisciplinary model for FASD diagnosis.
- Establishment of the WA State FAS Diagnostic & Prevention Network.
- Diagnosis of over 2,000 patients to date.

Prevention

- Publication of a lifetime profile of birth mothers of children with FAS and factors that enhanced and hindered their ability to achieve sobriety and practice effective family planning.

Surveillance

- Discovery that the prevalence of FAS among children in foster care born between 1993 and 1998 has significantly declined in King County. This is correlated with a significant decline in maternal drinking during pregnancy in the same years.

Intervention

- CDC-sponsored randomized control trial to assess an individualized, supportive, behavioral consultation intervention for parents and school staff of children with FASD.
- CDC-sponsored observational study of school-based social communication deficits among children with FASD.
- NIAAA-sponsored motor-sensory intevention research for children with FASD.
- Affiliation with NOFAS Washington State providing family support to children/adolescents with FASD.

Training

- FASD training of community professionals from WA State (1,000s trained).
- FASD training program to establish interdisciplinary FASD diagnostic teams

worldwide (>100 teams trained).
- Worldwide distribution of FASD diagnostic tools and software.
- Online training course for use of the FASD 4-Digit Diagnostic Code.

Research

- NIAAA: Alcohol teratogenicity studies, 1984-92.
- GE: FAS MRS study, 1991-92.
- Establishment of the FAS DPN database on over 7,000 patients, 1992 to present.
- Establishment of the FAS DPN Photographic Image Analysis Laboratory for clinical and research analysis of facial photographs, 1992 to present.
- Establishment of a FAS DPN Patient Registry as a resource for invitation of patients into FASD research studies, 1992 to present.
- CDC: FAS Primary Prevention study, 1992-97.
- CDC:FASD Behavior & Social Communication Intervention studies, 2001-10.
- NIAAA: FASD MRI/MRS/fMRI study, 2002-07.
- NIAAA: FASD Motor-sensory Intervention study 2009-14.
- NIH: National Children's Study Dysmorphology Assessment Instrument, 2010.

Literature

- Publication of over 150 research articles by the FAS DPN clinical/research team.