

FASD: From Discovery to Prevention in Washington State

Julie Gelo approached me a few months ago asking if I would be interested in contributing a piece to the Iceberg. I told her I would be happy to, time permitting. I figured I would stay true to form and submit a scientific-like article about the progress we have made in Washington State in diagnosing and preventing FAS. After all, it has been '30' years since the discovery of FAS right here in Washington State and much progress *has* been made. I sat down a few times to write this article, but nothing happened. After a few aborted attempts, it occurred to me what the problem was. I wanted to tell you a *story* about FAS, not the latest scientific discovery about FAS. More specifically, I wanted to share with you the remarkable progress Washington State has made in preventing FAS and acknowledge the efforts of three women whose contributions, substantially impacted the field of FAS.

FAS/FASD

You will remember in the April 2004 Issue of Iceberg, you were introduced to the new term FASD (fetal alcohol spectrum disorder). I will be using this term in this article, thus I thought I would remind you what it is. FASD is an umbrella term that reflects the full spectrum of outcome observed in individuals damaged by prenatal alcohol exposure. FASD is not a medical diagnosis. It is too broadly defined to serve as a meaningful diagnosis. In contrast, FAS is a medical diagnosis and it represents the subset of individuals with prenatal alcohol exposure who have growth deficiency, cognitive/behavioral problems and a unique cluster of facial features. FAS falls under the FASD umbrella.

The Discovery of FAS/FASD

To prevent FASD, we first have to discover it. So who discovered it? If you asked someone in the field, they would likely tell you it was discovered by David Smith, M.D. at the University of Washington in 1973¹. Most would also respectfully acknowledge the work by Dr. Lemoine in France in 1968². These are accurate accounts, but there is more to this story. Listed among the authors of the now famous 1973 publication is a woman named Christy N. Ulleland, M.D.¹. As it turns out, this woman is not just another co-author. She is the woman who discovered FASD. How so? Over the 20-plus years I have been in the field of FAS, I have heard bits and pieces of the story relating to her role in the discovery of FASD, but the stories were decades old and second and third hand. Last fall, 2003, I attended a national FAS conference in Atlantic City, New Jersey commemorating the 30th anniversary of FAS. It was a splendid conference, notable for both the impressive line-up of keynote speakers and, what will be remembered by all, as the infamous fire drill that required the entire conference hall be vacated 5 minutes before the opening keynote address. Once reassembled, one of the keynote speakers briefly outlined the early history of FAS. In so doing, he happened to mention Dr. Ulleland's name. He shared pieces of the story I had not heard before. On the flight home, I decided once and for all to find out the whole story. And who better to convey it than Dr. Ulleland. But where was Dr. Ulleland? Her name does not appear on any papers after the 1973 publication. Why not? When I returned to Seattle, I asked my co-workers to see if they could find Dr. Ulleland. Was she still practicing medicine? Did she still live in Washington State? Much to my delight, with a bit of ingenuity, my staff not only located Dr. Ulleland, but also arranged a phone conversation between the two of us. I cordially introduced myself and went straight to the point. I asked her "How was FAS discovered?" We spent the better part of an hour on the phone as she conveyed to me her recollection of the events. The place was the University of Washington. The year was 1968. And she was Chief Resident at the University of Washington Harborview Medical Center. While caring for infants admitted to a high-risk maternal infant clinic at Harborview, Dr. Ulleland noticed a few infants who were low birth weight, delayed in growth and development

and all had mothers who were chronic alcoholics. Remember, this is 1968. The community at large was not prepared to accept that alcohol might be harmful to the unborn child. Dr. Ulleland shared her observation with several of her colleagues (Richard Wennberg, Robert Igo and Nathan Smith). As astute clinicians, they knew it was important to rule out other potential causes like poor prenatal care, maternal smoking or poor nutrition? So they obtained a small sum of money to support Dr. Ulleland to conduct an 18-month investigation. Over the course of the study she identified 12 infants from the clinic with prenatal alcohol exposure, growth deficiency and developmental delay^{3,4}. She also collected compelling data that suggested alcohol played a key role. She submitted her findings, in the form of an abstract, to the Pediatric Research Society / Society of Pediatric Research annual meeting, to be held in May 1970³. Her abstract was accepted for presentation. As was customary in the Department of Pediatrics, residents whose abstracts were accepted for presentation did a practice-run in front of the pediatric faculty. It was at that practice-run that David Smith would learn of Dr. Ulleland's discovery. He expressed keen interest in her findings and asked to evaluate these children. As a dysmorphologist, he was interested in whether they presented with any physical abnormalities that might be reflective of a syndrome. He requested Dr. Ulleland bring all the mother/infant pairs into the clinic on a single day for him to evaluate. Mind you, many of these women were homeless and had not been seen for quite some time. This would be quite a feat to accomplish. While I was struck with this request, I was even more struck by the next detail. The day that was most convenient for Dr. Smith to attend the clinic to evaluate the children happened to be a day Dr. Ulleland would be out of town. I have to confess the word '*What?!!!*' escaped from me before I could hold it back. I conveyed to Dr. Ulleland my surprise (shock would be a more accurate descriptor) that after all the work she had put into this study, the day to be selected would be a day she could not be there. She understood my surprise, but also conveyed that Dr. Smith was a busy man. It is stories like this that help remind me how far we have come. Throughout our conversation, she spoke with the highest regard for David Smith. She described him as a "prince" of a guy. And made frequent reference to the contributions of her colleagues. She went on to share with me some rather comical stories of the trials and tribulations of locating these women and arranging transportation to the clinic with the help of a very devoted group of local taxi drivers. On the day Dr. Smith observed the children he was accompanied by his Fellow, Kenneth Jones, M.D. From here on out, the story is conveyed in the published literature^{1,5}. Dr. Smith did observe a pattern of malformation among some of the children identified by Dr. Ulleland. Dr. Smith would go on to identify additional children from his own records with similar characteristics. These children would serve as the study population from which the term FAS would be coined⁵. One last detail before I close... Unbeknownst to all attending the 2003 FAS Conference in Atlantic City, NJ commemorating the 30th anniversary of FAS (or was it the 35th anniversary?), the original abstract submitted by Dr. Ulleland for presentation at the American Pediatric Society/Society of Pediatric Research annual conference in 1970 was presented in none other than, Atlantic City NJ. The abstract was printed, not published, by the Society, thus the abstract cannot be readily found in the medical literature. The Society was kind enough to look through their archives and sent me a photocopy of the abstract. I have posted it on our website if you would like to read it, <http://depts.washington.edu/fasdpn>.

The Creation of the FAS DPN

Twenty-seven years later another young woman would enter the field, if only for a brief moment, and forever impact it. Her name is Andrea McNemara. The year was 1995. The place was the Washington State Capital in Olympia. Her contribution was Senate Bill 5688. Here is how the story unfolded from our end. I was meeting with my colleague, Sterling Clarren, M.D., one day in January 1995. The phone rang. It was an administrator from the University wanting to know what was going on down in Olympia regarding a Senate Bill that proposed to establish FAS

Diagnostic Clinics around the State with two professors named Clarren and Astley identified as responsible for training the clinics. “How remarkable”, we replied. “But to be honest, we have no idea what you’re talking about”. The University expressed some level of concern about this, for there are rules about faculty lobbying in Olympia and we should have come to the University first about this endeavor. We assured them that we knew nothing about this Bill, but were certainly most delighted to learn the state legislature took such an interest in FAS. We called the Senator who was sponsoring the Bill and introduced ourselves. He was delighted to hear from us and assured us he had every intention on calling us just as soon as he got a spare moment. We shared with him that we would be happy to come down the next day and provide him with some guidance on how the Bill might be revised just a tad to improve its chances of passing through the House and the Senate. In its current state, it would likely to be far too expensive to gain approval. He invited us to meet with him the next day. When we arrived, we exchanged introductions and took a seat. He thanked us for coming and immediately proceeded to pick up the phone to call his colleague who was working with him on this Bill. We overheard his conversation with his colleague. He said something to the tune of “I have Clarren and Astley in my office and they think your bill is *poorly written*.....” He looked at us and grinned. This was not exactly how we would have conveyed it. He asked his colleague to join us in the meeting. A few moments later a young women (twenty-something) walked in and introduced herself as Andrea McNemara, Session Staff Counsel. I’m sure we both looked a bit surprised, which was, no doubt, the Senator’s intent. He was having fun with us (and for the most part, we knew it). The Senator confessed it was not he who wrote (or initiated) this bill, rather it was Andrea. And she would be happy to meet with us and listen to what we had to share. Andrea invited us back into a high-ceilinged room and proceeded to share with us how this Bill came to be. So what would motivate a young woman like Andrea to propose such a Bill. Well, she shared with us, as a child, she grew up in a home in which her biological mother was a foster mother to many children who would come and go over the years. Andrea had the unique experience of watching the impact prenatal alcohol exposure had not only on the foster children living in her home, but the impact it would have on her own family, from a child’s perspective, as this condition failed to be medically recognized. When she grew up, she decided to do something about it. What she did was initiate a Bill that would recognize the importance of early accurate diagnosis of children impacted by prenatal alcohol exposure and established the Washington State FAS Diagnostic & Prevention Network of clinics that exist today. Little did she know that the establishment of this Network in 1995 would ultimately lead to the creation of the FAS Facial Photographic Analysis Software in 1996, the 4-Digit Diagnostic Code in 1997, the Foster Care FAS Screening program in 1999 and expand to over 70 clinics across the U.S. and Canada by 2004. I called her the other day to thank her once again for her efforts and share with her just how big an impact she had on this field.

Prevention of FAS

So where does prevention come into this picture. With the discovery of FAS in Washington State over 30 years ago, efforts have been underway for several decades to prevent FAS. These efforts span the full continuum of strategies from public health education (like warnings labels on liquor bottles and brochures in women’s clinics) to creation of alcohol treatment programs designed to better meet the needs of women with children. These efforts coupled with improved methods to screen, diagnose and track the prevalence of FAS have allowed us to confirm that these efforts are paying off. Here’s how we know. Starting in 1993, Washington State, along with 31 other states, has participated in a program called PRAMS (Pregnancy Risk Assessment Monitoring System). One purpose of PRAMS is to document the number of women who report drinking during pregnancy each year. Certainly what we would hope to see over the years is a decline in the number of women drinking during pregnancy. And that is exactly what we see in

Washington State. But this could be interpreted in two ways: 1) fewer women are truly drinking during pregnancy each year or 2) we have effectively educated women that drinking during pregnancy is harmful to the fetus, thus they know not to tell us they are drinking. Either interpretation can be seen as a public health accomplishment, but #1 would be the preferred outcome. If women were truly drinking less, one would expect to see a decrease in the number of children being born with FAS. As it turns out, we had a unique opportunity to assess this. In addition to tracking maternal drinking, we have also been tracking FAS through a screening program. Since 1999, the FAS DPN has been screening all children in a King County Foster Care Program for FAS⁶. Two thousand children have been screened to date. The results of this screening have confirmed that 1 out of every 100 children in this foster care population has full FAS. While these numbers are certainly discouraging, there are encouraging numbers to report. Among these children, there is a significant decline in the number born with FAS each year⁷. This decline correlates significantly with the same years women reported drinking less during pregnancy. More detailed accounts of these results can be found in publications posted on our website. These observations strongly support that FAS prevention efforts in Washington State are working.

Expansion Nationwide

One last story to share with you. It is now 1997, the FAS DPN is established and the 4-Digit Diagnostic Code created. The phone rings. This time it is Sr. Suzette Fisher, Co-Director of Sisters of Notre Dame Double Arc from Toledo Ohio. She has learned through the grapevine that we had established a diagnostic system called the 4-Digit Code and a Diagnostic Network called the FAS DPN and wants us to train her team to do the same. We shared with her that it was never our intention to start a training program. Our hands were pretty full just keeping our own Network up and running. But Sister Suzette was not one to take no for an answer. In the most cordial of ways, she for the most part informed us that her team would be in Seattle soon, and she had the utmost confidence in our ability to train them to do what we were doing. Turns out she was right. In February 1998, the first multidisciplinary team from out of state was trained. They went home and held their first clinic one month later and have been running a clinic ever since. From that day forward, a formal training program was established and to date, over 70 multidisciplinary diagnostic teams have been trained across the US and Canada. I often wondered if Sister Suzette realized what she started by that phone call back in 1997. In 2004, I had the opportunity to attend an FASD Center of Excellence Conference on Building Statewide Systems for FASD. The keynote speaker was First Lady Hope Taft of Ohio. In her talk, she spoke of the importance of recognizing FASD and establishing state systems for diagnosis, intervention and prevention. She spoke of the efforts, to date, in her State and referred to the early pioneering work by the Sisters of Notre Dame. I could not help but wonder if she was referring to the Sisters we met in 1998. I introduced myself to her after her talk and asked her if she had ever met a woman named Sr. Suzette Fisher. "Oh yes, of course", she replied.... Small world. I enjoyed sharing with her the role Sr. Suzette played in expanding the FAS DPN across the nation.

In closing, I would like to thank Christy Ulleland, Andrea McNemara, Sr. Suzette Fisher and all the unsung heroes in this field that have helped to improve the lives of children and families impacted by prenatal alcohol exposure. The accomplishments of Washington State did not happen overnight. Nor did it take 30 (or was it 35?) years. I have little doubt we have made measurable progress each and every day. What took 30 years was figuring out *how* to measure our progress.

References

1. Jones KL, Smith DW, Ulleland CN, Streissguth AP. Pattern of malformation in offspring of chronic alcohol mothers. *Lancet* 1973;i:1267-1271.
2. Lemoine P, Harousseau H, Borteyru JB, Menuet JC. Les enfants de parents alcooliques: Anomalies observees, a propos de 127 cas. *Paris, Quest Medical* 1968;21:476-482.
3. Ulleland CN, Wennberg RP, Igo RP, Smith NJ. The offspring of alcoholic mothers. 1970, p. 93. Printed (not formally published) in the Annual Conference Abstract Issue by the American Pediatric Society/Society of Pediatric Research. (see abstract below)
4. Ulleland, Christy N. The offspring of alcoholic mothers. *Annals New York Academy of Sciences*. 1972;197:167-169. (see article below)
5. Jones KL, Smith DW. Recognition of the fetal alcohol syndrome in early infancy. *Lancet* 1973;ii:999-1001.
6. Astley SJ, Stachowiak J, Clarren SK and Clausen C. Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *J. Pediatrics*, 2002;141(5):712-717.
7. Astley SJ. Fetal Alcohol Syndrome Prevention in Washington State: Evidence of Success, *Ped Perinatal Epidemiology* (Submitted, April, 2003, In Press, September 2004).