

FAS TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

FASD: Diagnosing the Spectrum-Part I

Jocie DeVries

Sometimes life is just fun. 2005 was a roller coaster year for us, filled with all kinds of exciting events, some good and some bad. But it wasn't until we started working on this issue of FAS Times that we realized just how much *positive* progress has been made in diagnosing the spectrum of conditions in FASD. It all started with a big wish we made when we published *Nurture: The Essence of Intervention* in May.

The goal of our book was two-fold. We wanted to create a beautiful photo gallery of affected individuals as a gift of encouragement to doctors, psychiatrists and psychologists that positive things can and do occur when children, youth and adults are accurately diagnosed and nurtured by a loving family. We also hoped that publishing the medical and mental health histories and photos of affected children, youth and adults (many of whom had been diagnosed during the period of time in the field when the term FAE was used as a diagnosis) might encourage the current professionals to consider diagnosing FAS-related conditions, even when the classic facial features are not present.

For so many years, parents have been told by family practitioners that there is no benefit in getting a diagnosis because nothing can be done about FAS anyway. We believe the nurture book is helping to raise public consciousness that a medical diagnosis related to prenatal alcohol exposure can be a pivotal experience for children and families as far as understanding what is going on and then finding out how to improve their quality of life.

Therefore, this issue of FAS Times features interviews and information from eight doctors and psychologists from across America who diagnose conditions caused by prenatal alcohol exposure. Interestingly, when you meet these professionals (most of them researchers) and take a look at their different diagnostic perspectives, the full spectrum of disabilities and mental health disorders which now fall under the umbrella term Fetal Alcohol Spectrum Disorder (FASD) fall into place, thus creating a complete, 3-D profile of the cognitive and physical disabilities from prenatal alcohol exposure.

During the process of conducting the interviews, writing the articles and then re-reading all of them, two important issues came to the surface. First, we were surprised to find that there are at least three other researchers and/or clinics that are conducting longitudinal studies of birth cohorts of children who were prenatally exposed to alcohol. Before this, we thought that Dr. Ann Streissguth was the only researcher doing this.

The second and most exciting discovery is that there are numerous medical doctors and psychologists who are already using, or are developing, methodologies and criteria to diagnose children (and even adults!) who have been affected by prenatal alcohol exposure but do not have the classic facial features of FAS. These doctors have been quietly blazing trails for the last several years by leading the way in diagnosing conditions such as Alcohol Related Neurodevelopmental Disorder (ARND). This is such an encouragement to us parents, especially those of us who are still seeking a diagnosis for our children (regardless of age).

Another piece of good news is that we found so many doctors and researchers to interview that we couldn't fit all the information in one issue of FAS Times. So if you are one of these parents still seeking a diagnosis for your child, and none of these professionals are in your area, watch for our next (Spring 06) issue of FAS Times where we will be printing the rest of the interviews.

This is a time to be especially thankful. I feel like we are at the dawn of history in really helping affected individuals and their families. Read and enjoy the stories of these medical doctors and psychologists. Then dream big dreams. Together we are finally making progress in diagnosing affected individuals, so we can better care for them with understanding and compassion. And when compassion bears its full fruit, our children will reap a harvest of self esteem—and stigma will be a thing of the past. ♥

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2005/2006

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Ira Chasnoff, MD

President, Children's Research Triangle; Professor of Clinical Pediatrics, University of Illinois College of Medicine, Chicago

When asked what was it that originally brought him into the field of FAS, Dr. Ira Chasnoff replied, "In 1976 I founded a developmental clinic because I was interested in helping children with disabilities. However, I quickly realized that many of the children with the most serious disabilities were children born to mothers who had used alcohol or heroin during pregnancy. In order to help the children, we also decided to open one of the first treatment programs in the country for pregnant women. As a pediatrician, I provided pediatric and development care to the children whose mothers were in substance abuse and prenatal care services in our program. For the first 10 years our program was purely a volunteer program, with a budget of \$0. That's why I become frustrated today when people say they don't have money to serve children and families!"

Q: Do you diagnose FAS in the context of research and/or clinical practice?

A: I'm both a researcher and a clinician.

Q: What are your primary areas of concern?

A: Diagnostic criteria, prevention, intervention and treatment of affected children.

Q: Do you diagnose FAS in a typical medical setting or in a multi-disciplinary professional team?

A: Multidisciplinary team.

Q: How many patients do you estimate you have diagnosed during your career?

A: 8,000-10,000. (For the last 8 years, we have seen about 800 children per year with 80% of them meeting criteria for FAS or ARND.)

Q: How many patients do you see on a monthly basis?

A: Between 50 to 70.

Q: Where do your referrals typically come from?

A: Child welfare system, schools, other physicians.

Q: How many of these patients are coming to you because they or their referring agent believe they have FASD?

A: About 50% are asking if alcohol effects

are present; typically the referral is because of behavioral or mental health problems.

Q: What percentage of your patients actually receive a diagnosis related to prenatal alcohol exposure?

A: 80%

Q: What diagnoses do you typically make?

A: FAS and ARND. It would be highly unusual for us to see a child with ARBD.

Q: Do you primarily focus on the facial features of FAS?

A: Absolutely not.

Q: Do you diagnose other conditions (such as disabilities/mental health disorders) caused by prenatal alcohol exposure in addition to FAS?

A: Yes.

Q: What diagnostic criteria do you use for these conditions?

A: Diagnoses are based on DSM-IV criteria. We do a lot of work with children who have FAS/ARND plus mental health disorders.

Q: Do you have an ongoing doctor/patient relationship with the people you diagnose?

A: Yes.

Q: Do you or a diagnostic team develop a long term treatment plan, including regular follow-up visits?

A: Yes-we believe this is key.

Q: What kind of long term follow up would you like to see for those with FAS?

A: Children and adults with FAS need a comprehensive continuum of care that includes health, mental health, and educational interventions, and as the children reach adulthood, they require employment training and support.

Q: What is your dream for the future of diagnosing this disability?

A: For all three categories (FAS, ARND, ARBD), we need a universal screening approach that focuses on early recognition of risk, grounded in developmental and behavioral screening, complemented by facial analysis. Key to this is Medicaid and the insurance companies' recognition of the disorder, so that all diagnostic and treatment work is reimbursable. ♥

Children's Research Triangle

Appointments: (312) 726-4011

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Claire Coles, PhD

Director of the Fetal Alcohol Center, Marcus Institute; Professor of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta

Dr. Claire Coles has been a strategic pillar in FAS research since most of us parents first learned about the disability in the early 1990's. FAS*FRI's first discovery of her work was in 1997 when we discovered a research article that she had written, differentiating ADHD from FAS (FAS Times, Summer 1997). After reading her research paper on the subject, we knew that we had found someone who genuinely understood FAS—at least one of the subtle deficits caused by prenatal alcohol exposure that parents deal with on a daily basis. We were excited because, as is typical with us, we are ever on the lookout for ways to separate the core behavioral traits of FASD from other co-occurring conditions.

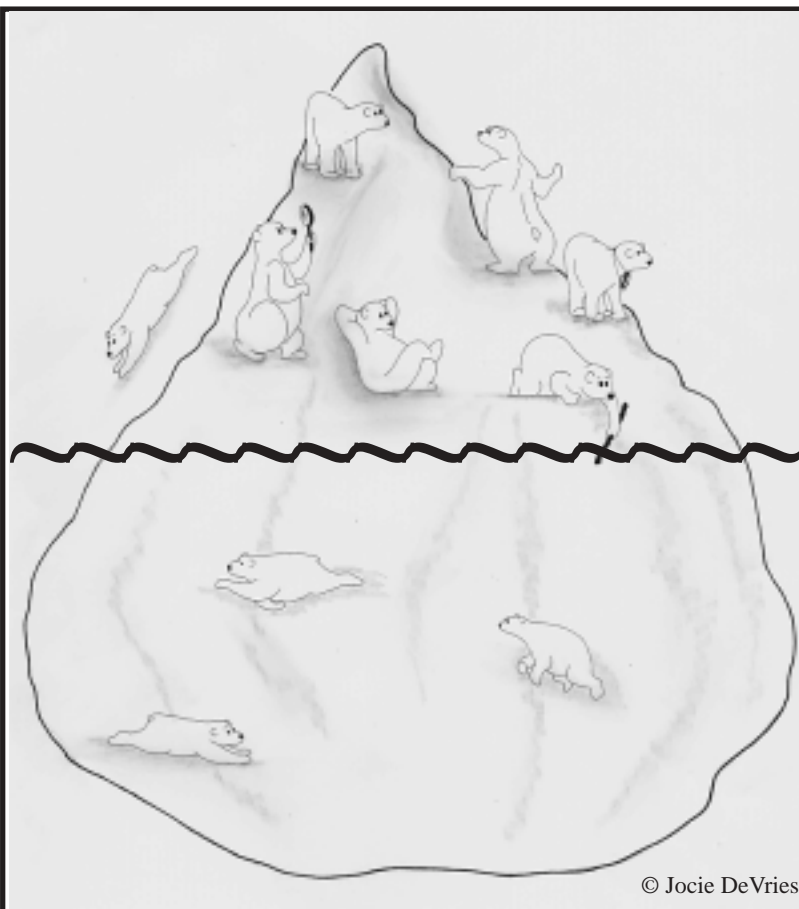
As a health care professional, Claire Coles divides her time between research and clinical practice. When I asked her how she got into the field of FAS, she laughed and said, "Well, it was simple really. I was a single mom, I had just finished school and I needed a job. I was interested in babies so I applied for a post doctoral position in the Department of Psychiatry and Behavioral Sciences at Emory University in Atlanta, Georgia. There I met Arthur Falek, who became my friend and mentor and we began studying alcohol and drug exposed babies.

"The Maternal Substance Abuse and Child Development (MSACD) Prevention Program where I work, began as the Fetal Alcohol Syndrome Screening Project and evolved into a longitudinal study of children exposed to alcohol prenatally, *a cohort that we are still following today*. Now the cohort consists of 430 individuals. The study began in 1981, when the Georgia Legislature had the foresight to establish a program to begin screening pregnant women for alcohol use in order to identify the extent of the problem in Georgia, as well as methods for prevention in this group. The project is currently dedicated to the prevention of the negative consequence of maternal substance abuse and provides a range of prevention services to state agency- and community-based staff across the state."

Dr. Cole's other position is at the

FASD: Diagnosing the Spectrum

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“FAS is
only the
tip of
the
iceberg.”

Ann
Streissguth,
PhD

Marcus Institute where she serves as Director of the Fetal Alcohol Syndrome and Drug Exposure Clinic. The clinic provides a comprehensive array of diagnostic services, evaluations and support programs to people with developmental disabilities and their families as well as those who live and work with them. It is an affiliate of Kennedy Krieger Institute at Emory University. The mission of the Marcus Institute is to bring hope to people in all the little things that help children reach their potential. Dr. Coles explains, “As we see it, the problem is that the search for effective services for children with disabilities and learning problems can create a constant struggle for their caregivers. The purpose of the Marcus Institute is to reduce the stress of that search by offering the most comprehensive diagnosis, therapy and care management possible under one roof.”

The health care professionals of the Marcus Institute create the largest team dedicated to child development, in one facility, in the state of Georgia. In addition, the affiliation with Emory University and Kennedy Krieger Institute affords staff at the Marcus Institute access to a wealth of academic and medical resources for their patients and families. A few days ago we

called and asked Dr. Coles a few questions about the diagnostic process at the clinic in Georgia.

Q: How many patients do you see on a monthly basis?

A: 16, or about 200 a year for diagnosis. More for therapy, educational and social work services. We have about 160 appointments with patients per month.

Q: How many of these patients are coming to you because they or their referring agent believe they have FASD?

A: Most of them. Some are exposed to other drugs, including prescription drugs.

Q: What diagnostic criteria do you use?

A: For FAS - A confirmed history of alcohol exposure, facial dysmorphism, growth deficiency and central nervous system damage. For Partial FAS - A confirmed history of alcohol exposure and some of the other characteristics.

Q: Do you have an ongoing doctor/patient relationship with the patients you diagnose, including regular follow-up visits?

A: Yes

As you know, we at FAS*FRI believe that there is a core set of behaviors that are

typical, i.e., an FASD Behavioral Phenotype. So my final questions are:

Q: What would the diagnosis be for a patient who comes in with a history of heavy fetal alcohol exposure, evaluations and imaging that document cognitive significant impairment, and all the other diagnostic criteria except the facial dysmorphism?

A: We would evaluate this patient carefully to rule out any other causes for the behavior and the neurodevelopmental effects. However, with this profile, the diagnosis would probably be partial FAS or ARND.

Q: What is your research showing about the common behavior traits of FAS and ARND?

A: The most common finding that we see is called “arousal dysregulation.” Some examples of this are uneven sleep patterns, hyper arousal and inability to calm down during the day. They get excited too easily, get stressed too easily, have problems with transitions, etc. These problems can develop into difficulties with behavior regulation and, eventually, behavior problems. In a sample of drug and alcohol exposed children—we have been documenting these problems and following these kids for eight years now—this dysregulation seems to be something that we consistently find. ♥

Robert Sokol, MD

Director, C.S. Mott Center for Human Growth and Development;
Distinguished Professor of Obstetrics and Gynecology,
Wayne State University School of Medicine, Detroit, MI

When we asked what brought Dr. Sokol into the field of FAS, he answered, "Well, I had been seeing patients in my OB/GYN practice and doing perinatal research for several years, when one day one of my colleagues called to ask me if I had seen the paper on Fetal Alcohol Syndrome in the Lancet written by Drs. David Smith and Ken Jones. When I answered no, that I hadn't, he suggested that I might want to take a look at it. He wanted to know what I thought about the concept of the possibility that birth defects could be caused by women drinking during pregnancy.

"After reviewing the article, I went back to my office and did a simple search of my database. I could do that because I had already been keeping track of high risk pregnant women, including those who were known to have problems with alcohol during their pregnancies. Because of the nature of our existing database, it didn't take us long to see that pregnancy outcomes were much worse with those women. Then we did a systematic review of the charts and found a ratio of 3 per thousand of babies that were definitely affected. That's how I became involved in the FAS research field. I wanted to see what I could do in my OB/GYN practice to help bring about better outcomes for women and their babies. We applied for and received a grant from the National Institute on Alcoholism and Alcohol Abuse and started documenting our findings. Our first papers were published in 1980.

"The next thing I knew, I was being called to testify on our findings by the United States Senate. They thought our longitudinal population studies were unique because as an OB/GYN clinic, we have the data on the babies starting from conception. A cohort of these children were followed into early childhood; since then my colleagues and I have followed several large cohorts, the longest for almost 20 years. These children range from those who have had no alcohol exposure

to those who were heavily exposed."

Q: What is the most important data that you have identified since you began working to prevent drinking during pregnancy in your OB/GYN practice?

A: For one thing, we've learned that when women are questioned directly about drinking during pregnancy, under-reporting can be a real problem. Denial can be substantial, a fact not surprising to those who deal with problem drinkers. Consequently, our research group and others have worked to develop screening tools that are not confrontational and are less likely than direct questions to trigger denial; these simple questionnaires assess drinking-related problems in clinical settings.

Q: What other research outcomes come to mind?

A: Our group and other groups have confirmed that simple brief screens, such as the T-ACE, TWEAK and AUDIT can be very useful in identifying women who may be drinking enough to damage their unborn offspring. Further, brief interventions can be useful in reducing this behavioral risk.

Q: What common traits are you finding as you follow these children up through adolescence that seem to be typical?

A: The children are growth deficient at least as young children, there is a dose/response correlation involved in the damage as measured by anatomic birth defects; often IQ is reduced; and there are hyperactivity/attention problems with these children/youth. Drs. Joe and Sandy Jacobson and Dr. Ginny Delany-Black are the lead investigators in these developmental studies.

Q: What type of community follow-up is available for these mothers and babies, once the children are born?

A: In this area, I work with Dr. John Hannigan. The basic premise is that we are primarily looking at FAS and ARND diagnoses with lifelong negative consequences in learning, memory and adaptive responses. Early intervention means looking for ways to help with the neurobehavioral damage of prenatal alcohol exposure. Often the family must try to modify the environmental structure of the child/youth; this path can be very slow and painful for families. My original goal of getting into the field is that I could somehow make a contribution to healthier

babies. In the meantime I have grown to deeply appreciate the difficult road that families have to travel. I would hope that in the future scientists and families could collaborate more closely. By working together, we will have the best chance at reaching our goals, i.e. better outcomes for babies and mothers. ♥

Alan Unis, PhD

Director of Psychiatry, Sacred Heart Medical Center,
Spokane, WA

Dr. Alan Unis first became interested in how prenatal exposure to substances affects behavioral development in 1971 after he began doing some controversial research on rat pups. During that time, the prevailing thought in child development and child psychiatry was if children were seriously emotionally disturbed, it was due to one of two factors. Either they had learned dysfunctional behavior from imitating others with bad behavior or they had not been effectively nurtured during their early years. Dr. Unis' early research, in which rat pups were given a pulse of estrogen on their first neonatal day, documented abnormalities in many social behaviors and in physiologic functioning. This study was one of the first research protocols that showed clearly deviant behavior could be caused by prenatal exposure to a foreign substance. As his career continued and research blossomed, he met and worked for many years with Dr. Sterling Clarren at the University of Washington (UW), where he grew interested in Dr. Clarren's animal research which showed that the disruptive behaviors reported by parents raising children with FAS/FAE were not caused by bad parenting but by exposure to alcohol during fetal development. Dr. Unis' specialty evolved into identifying medications that might help soften some of the behavior problems of children with neurological damage who were referred to him.

Q: When and why did you leave the University of Washington and move to Spokane?

A: I became frustrated with the fact that many of the medications we were commonly using for children and adolescents with psychiatric disorders had not been systematically tested in young people and many pediatricians did not have enough training in developmental medicine to thoughtfully use psychotropic medications. So when a pharmaceutical company approached me to go to work for them

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Sterling Clarren, MD

Clinical Professor of Pediatrics,
UBC Faculty of Medicine;
CEO, Canada Northwest FASD
Research Network, Vancouver, BC

As most readers of FAS Times know, my son Russell was diagnosed with FAS by Dr. Sterling Clarren in autumn 1990. At that time Dr. Clarren was on staff at Children's Hospital and Medical Center in Seattle, Washington. When we decided to focus this issue of FAS Times on the current state of the diagnostic process, of course reconnecting with Dr. Clarren was my first thought. It took a while, but I finally found him. He and his wife Sandy are now living and working in Vancouver, British Columbia. The Canadian Northwest FASD Research Network,¹ which he now heads, was created in 2004. It is a collaborative effort of provincial and territorial governmental ministers from the four western provincial and three northern territorial governments with full inclusion of stakeholders, including Jan Lutke (adoptive mother and advocate for her 12 children who are affected by FASD), who is the Program Manager. The lead agency for the network is the Provincial Health Services Authority of British Columbia.

When asked about the goals of the project, Dr. Clarren answered, "Everything—surveillance, prevention and intervention. The region already includes 18 clinic sites. Through working together we can develop a consistent model for diagnostic services and demonstration projects with a consistent implementation plan across Northwest Canada. There are over 150 projects ongoing in prevention and intervention and this gives us a real chance to learn from each other's experiences. My dream is to have a network that is the best it can be at any moment in time. It's great to be in a position to see all levels of research, prevention and intervention being studied by one cohesive public effort."

Q: What diagnostic criteria are you using in this project?

A: We basically use the 4-Digit Code² but it has been modified and tweaked through a collaborative study across the provinces. The diagnostic system up here is now called the Canadian FASD Diagnostic Guidelines. Our goal is to establish best practices in the projects that we are working on.

Q: What do you believe is the key to

success with affected individuals?

A: I have always believed that getting a diagnosis is just the first step. The key is having a consistent way to lead a team of professionals, including affected individuals and their families, to identify any other disorders that may also be present and, through all of this information, have the ability to develop a comprehensive treatment program.

Personal note from Jocie: In the beginning days of FAS*FRI (1990) there were three mothers (Vicky McKinney, Linda La Fever and I) who, independently from one another, developed FAS presentations to increase public awareness on the consequences of drinking alcohol during pregnancy. Eventually we met each other in this process and instantly bonded because of our common experiences and our mutual determination to increase public awareness that this condition was preventable. Another thing we had in common was that Dr. Clarren had seen our three affected children in his clinic. Because our children's diagnoses came from him (the only FAS expert in the state at the time), we had the confidence to become bold in our public awareness efforts. Thus a movement was born. We are forever grateful for the fact he allowed us to pester him to death for information (which is how we came to be known as the FAS Pests of the West). The knowledge base, which he and other researchers provided became the scientific cornerstone of the FASD Collective Family Experience. ♥

¹A comprehensive article on this network can be found at www.fasiceberg.org/newsletters/Vol15Num4_Nov2005.htm#network

²Astley SJ, Clarren SK. (2000) Diagnosing the full spectrum of fetal alcohol exposed individuals: Introducing the 4-Digit Diagnostic Code. *Alcohol and Alcoholism*, 35 (4): 400-410.

Larry Burd, PhD

Director, North Dakota FAS
Center: Co-Principal Investigator
of the Four-State FAS Consortium

Larry Burd has been a supporter of the Collective Family Experience for a long time. We parents at FAS*FRI first met him during the FAS National ARC Summit in Maryland in 1993. The conference was hosted by the National ARC and was truly an inclusive summit. There were FAS researchers such as Dr. Burd; professionally-

run groups such as the ARC, March of Dimes, and NOFAS; and, surprising for a conference as early as 1993, representatives of family-run groups (including FAS*FRI), some of which were invited to give keynote presentations. Of course this was the ARC, which has a long tradition of understanding the difference between professionally-run groups and family-run groups.

As parents came together and got acquainted at this first national FAS conference, Larry Burd seemed unique to us because he evidently preferred to hang around the parents and listen to our conversation instead of sitting with the more sophisticated professionals in our midst; on the other hand, maybe he just had a feeling we were going to be causing trouble and he wanted to know where we were headed.

When Dr. Burd was asked what it was that originally brought him into the field of FAS, he said, "I became curious about my patients who obviously had learning and behavior problems without a known cause." Dr. Burd has been working in the FAS field for over 30 years and has proven to be a great friend to affected children and their families.

Along the way, he has gained a lot of expertise in understanding how to work with birth families and that's because he listens. Interestingly, he and Linda La Fever (FAS*FRI's Birth Mom Mentor) have developed a camaraderie in their mutual tough love approach to parents who are still practicing their addiction. They believe the first order of business must be to protect the children and a close second is getting the mothers into treatment. Only in this way can the children be in a safe place and the mothers can begin their recovery.

Q: Dr. Burd, do you work in the context of research and/or clinical practice?

A: Both

Q: If research, what is your primary area or areas of concern?

A: Diagnostic criteria, prevention and intervention

Q: Do you diagnose FAS by yourself or in concert with a multidisciplinary team?

A: We use a team approach.

Q: How many patients do you estimate that you have diagnosed during your career?

A: 650

Q: How many patients do you see on a monthly basis?

A: 25

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Colleen Morris, MD

Chief, Genetics Division, Dept. of Pediatrics, University of Nevada School of Medicine, Las Vegas, NV

Dr. Morris first contacted FAS*FRI in July, 2004 when she expressed interest in our Behavioral Screening Tool, now called the FASD BeST. She indicated that her group would be most interested in collaborating with us on it. "We are studying genotype-phenotype correlation in Williams syndrome. (I collaborate with psychologist Dr. Carolyn Mervis at the University of Louisville.) One of our current projects involves the use of behavior questionnaires and structured interviews to evaluate social disinhibition and anxiety in Williams syndrome (WS). We could add your instrument to our test battery for WS and also use it in our FAS population, to determine if it discriminates between these two neurodevelopmental disorders."

In the same communication, she mentioned that she always enjoyed reading FAS Times from both the professional and personal standpoint (one of her adopted sons has FAS). She went on to say that she first truly understood his viewpoint one Saturday morning when she asked him what his plans were for the day and he responded, "Mom, I live in the NOW!!"

Tragically, she shared with us, only a few months after this, her son was killed in a rollover car accident—"despite being reminded to wear his seatbelt whenever he was in a car, or truck, or airplane...for his whole life—he was not wearing a seatbelt. He died 10 days after his 20th birthday. ("I'm not a teenager anymore, so I'm going to get my act together," he had said.) We miss him horribly, of course. I can say that he taught me a great deal about FAS, about what is important, and gave me the opportunity to be a better physician and advocate."

When we asked Dr. Morris about who did the diagnosing for her research on FAS, she replied that she did and then explained her method of diagnosing FAS with us: "Everyone knows that it is relatively easy to recognize the child with FAS who has everything—the face, neurologic features, growth retardation, and the behavior. Most physicians will be comfortable making that diagnosis after they have learned to rec-

ognize it. However, most physicians are not as comfortable making a diagnosis when there are fewer physical features to rely on.

"In 1996, after the Institute of Medicine Report was published, our genetics program decided to classify individuals as FAS 1 - FAS 5 [as defined below], 'not FAS,' or 'not sure.'

*FAS 1 is the classic full blown phenotype;

*FAS 2 is FAS 1 without documentation of alcohol exposure (e.g., child adopted from a foreign country);

*FAS 3 is what has been called partial FAS. To diagnose FAS 3, we require 1) at least one facial feature: short palpebral fissures (less than 10th percentile), thin upper lip, smooth philtrum. We also list supportive physical features such as hockey stick flexion crease, midface flattening, etc. 2) either growth retardation, OR neurologic abnormality (structural or functional), OR the behavior profile 3) history of prenatal alcohol exposure;

*FAS 4 is alcohol related birth defects (ARBD); and

*FAS 5 is alcohol related neurodevelopmental disorder (ARND) which has no physical findings of FAS, typically cannot be diagnosed (at least by me) until the child is older (around age 5-6 years), when it is possible to test for maladaptive behaviors and evaluate attention, etc. (In my experience, children who clearly have abnormal behavior as toddlers usually have neurologic abnormalities, too, and get a diagnosis of FAS 1 or FAS 3) For the kids that I see in clinic at age 3 that have had prenatal exposure and are at that point physically and developmentally normal, I ask to evaluate them again in a couple of years. I talk to the parents about parenting strategies for FAS anyway, since I don't have a definitive diagnosis at that point.

"According to the diagnostic criteria published by the Centers for Disease Control in 2004, both FAS 1 and FAS 2 would qualify for a diagnosis of FAS.

"You may be interested to know that we also collaborated in an anthropometric measurement study that did allow us to differentiate 'partial FAS' from normal, using 6 craniofacial measurements. Copies of the papers are available. (I have also been using this technique in helping to make a diagnosis.) I have tried the 4-digit

system¹ of Astley and Clarren, but currently only use their published photos of the upper lip and philtrum in FAS for teaching purposes.

"In our community, the developmental behavioral pediatrician and the pediatricians who work for the early intervention program have been trained by me to make the FAS diagnosis. If they have a case that they are not sure about, they send the child to me. We have also been successful in teaching the school nurses to recognize features and make referrals for diagnosis, and are currently trying to set up a 'one stop shop' FAS clinic in Las Vegas where kids can get the diagnosis and then referrals for services.

However, I am still not satisfied with the way we are making the diagnosis of FAS 5, and am looking for a more standardized way of evaluating the behavior. Currently, I ask the parents/caregivers a lot of behavioral questions that are based upon my own experience as much as traits that have been detailed in the literature."

In the time between our first communications with Dr. Morris and the middle of January, she and her colleagues have set up their FAS clinics which have been well-received. They have also had a town hall meeting about FAS in Las Vegas and another one in Reno. She is currently trying to work on getting services in Nevada for adults with FAS who "age out" of the meager services available for children.

Q: What was it that originally brought you into the field of FAS?

A: I am a geneticist and adopted a child with FAS.

Q: How long have you been in the field?

A: 20 years.

Q: Do you diagnose FAS in the context of research and/or clinical practice?

A: Both.

Q: If research, what is your primary area or areas of concern?

A: Diagnostic criteria and intervention.

Q: Do you diagnose FAS in a typical medical setting or in a multidisciplinary team?

A: Until this year, it was in the setting of a general genetics clinic. Since mid 2005, it has been part of a multidisciplinary team.

Q: How many patients do you estimate

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¹Most current version of this diagnostic code as used at the University of Washington: <http://depts.washington.edu/fasdpn/htmls/4-digit-code.htm>.

A Little Community that Could

Jocie DeVries

When Ann Streissguth asked me what the agenda would be, I had to think. I really hadn't developed an agenda. I just knew that when you put great people in a room together, special things happen.

It all started when Vicky McKinney moved to a town called Mossyrock. After a few weeks of transition from living in the city all her life to country living, she started talking to me about these two dynamic young women she had met. Coincidentally (if you believe in coincidence) they were also raising children with Fetal Alcohol Spectrum Disorder (FASD). Eventually I was able to meet Dot Workman and Susan Bradly, myself. Their combined energy level (focused on building good, healthy lives for their children) was so contagious I had to laugh. They were so encouraging to be around, it made me want to break out in song, "I am Woman, hear me roar!" After all, they had the energy and optimism of *youth*.

It was fun to watch them bond with Vicky. She had been advocating for their kids for several years before she moved to Mossyrock and had recognized their leadership qualities immediately. It wasn't exactly that she picked *them* for leadership, although she did. In reality, they came along side of *Vicky* and decided that she would be their mentor in all things FAS. So of course, I knew they were smart. As master advocates they have learned to be effective by utilizing the I.D.E.A. education laws to help their four affected children not only survive public school, but thrive. One of their most impressive characteristics is that they had already learned to *document* everything.

Susan and Dot are first cousins, living in the small town of Mossyrock, nestled in the woodlands and along the rivers and streams of the Cascade Mountain range in Washington State. Between the two of them, they have a total of eleven children. Along life's way they became foster parents, eventually adopting a total of six affected toddlers who soon snuggled into their loving, extended family circle.

One of their more interesting adventures is the collaboration that they have developed with a pediatrician in the nearby town of Centralia. Dr. Pope lived in a town not far from Mossy Rock and Centralia, where he and his wife built a children's clinic and spent

their careers helping parents raise healthy, happy children. After he retired, Dr. Pope and his wife moved to Centralia to focus their attention on helping families who have children with special needs. They formed a non-profit organization called Pope's Kids Place, bought property and gradually began remodeling the buildings on the property with the help of other community leaders and Boy Scout troops. Pope's Kids Place now provides medical and dental care, therapeutic daycare for children with special needs and a respite center for parents. From the beginning, Dr. Pope and his staff were interested in identifying whatever conditions were troubling his little patients. Of course it wasn't long until it became apparent that fetal alcohol exposure was a major factor for some of these children.

Susan and Dot met Dr. Pope after adopting their respective children. Eventually five of their adopted children were diagnosed with Fetal Alcohol Syndrome and related co-existing mental health conditions. Having lived in one small community their entire lives, they recognized the need for community education not only for their own children but for other affected children in the community. So they enlisted Vicky to help them. They put their collective talents to work and made a presentation to a local interagency project, Families Moving Forward, thus bringing information and understanding of FASD to professionals in the community.

In January 2005, the community held their first conference on FASD, which was sponsored by *Pope's Kids Place* and the Families Moving Forward project. Vicky, Dot and Susan served as facilitators of the conference. Remarkably for such a small town, over 200 parents and professionals came to learn how to identify, understand and help affected children.

Now back to early December 2005. As I sat at my desk, pondering the agenda for the meeting with Dr. Streissguth and Dr. Pope, I shook my head in amazement as I thought of all that had been accomplished during the previous eleven months. Later that day Vicky, Ann Waller and I finished the agenda. First we had an introduction

of the participants, which included a special guest, Mr. Fred Garcia, the Chief of the Office of Program Services in the Washington State Division of Alcohol and Substance Abuse and then a specific timeline to guide us through the afternoon. But as a person who operates primarily through intuition, I knew the result would come from the magic in the room when great minds and deep passions for vulnerable children came together. I was not disappointed. The vitality of the personalities and the devoted professional minds of Dr. Streissguth, Dr. Pope, Mary Chmelik, Fred Garcia, and the parent advocates (Vicky, Dot, Susan and I) came together in a very special way. Several specific outcomes came out of that meeting, which may be of interest to those of you who also work in the field of FASD.

The first is the fact that one medical doctor can make an enormous difference in the lives of affected children. Dr. Pope is a good, humble person who is focused on learning what it takes to diagnose and help children with FASD who live in his community. His determination to move forward is an immeasurable gift of encouragement to Vicky, Dot, Susan and me. The unique thing about encouragement is that it generates hope—and sometimes hope is all a mother needs to build a better world for her child.

The second encouraging outcome of the meeting came from the special insight of Fred Garcia. The principle behind his contribution relates to one of the most frustrating elements that parents face when it comes to FAS: the fact that the government workforce is so ill-prepared to identify and work with affected children, youth and adults. Yes, we want our local doctors to be able to diagnose, but we also need educators and social service providers to accept these diagnoses as valid. If world-class FAS researchers and dysmorphologists such as Dr. Ken Jones (San Diego State University), Dr. Luther Robinson (State University of New York at Buffalo) and Dr. Eugene Hoyme (Stanford University School in California) can train pediatricians around the world (South Africa, Russia and

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Community that Could...

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Denmark) to diagnose FAS and related conditions, then medical doctors in our local communities can also learn to accurately diagnose them. Fred Garcia listened carefully to the conversation and, understanding the practical implications of this dilemma, offered to work with us to try and identify the appropriate people in state government for us to discuss our concerns and goals.

The third positive outcome concerns the identification and diagnosis of children who were disabled by fetal alcohol exposure but do not have the facial features. This diagnosis is called Alcohol Related Neuro-developmental Disorder (ARND) by the Institute of Medicine and is one of the most neglected topics in the field of FASD according to the Collective Family Experience. Fortunately, this is where the research of Dr. Ann Streissguth and her colleagues, Dr. Fred Bookstein and Dr. Paul Connor, shine. At the December meeting she agreed to return to Centralia in the spring and talk to parents and professionals in the Families Moving Forward project about her ARND research. She also encouraged all of us to support and work with Dr. Connor as he develops the assessment and evaluation protocols at the new, practical, fee-for-service clinic that he is developing to serve affected children and youth, their families and professionals wanting to provide support services to these individuals.

As you can see this is an exciting time for parents in Mossyrock, Washington. They have shown us that one kind doctor and three determined mothers can create a little community that could. ♥

Larry Burd...

Continued from page 5

Q: Where do your referrals typically come from?

A: This area of the U.S.

Q: How many of these patients are coming to you because they or their referring agent believe they have FAS?

A: About 30%.

Q: What percentage of your patients actually receive a diagnosis related to prenatal alcohol exposure?

A: 15%.

Q: What diagnostic criteria do you use?

A: We have a scoring system (score 0-120). It takes about 1 hour for the physician to complete the exam and fill out the form. The tool has a component for exposure assessment and scores for signs of FASD. We have revised this tool extensively over the past 15 years. The tool also encourages using available pre-existing data, if it is judged to be reliable, to reduce the time and cost of assessment.

Q: Do you primarily focus on the facial features of FAS?

A: No, we believe this is only a small portion of subjects with FASD.

Q: Do you diagnose other conditions (such as disabilities/mental health disorders) caused by prenatal alcohol exposure in addition to FAS?

A: Yes, this is the most common manifestation of FASD.

Q: What do you call these diagnoses/conditions?

A: Co-morbid disorders. These are disorders which are often but not always seen in patients with an FASD, e.g., ADHD, mental retardation, depression, seizure disorders, congenital heart defects, visual impairment, etc.

Q: What diagnostic criteria do you use for these conditions?

A: If it is a mental disorder, we use the DSM criteria. If it's another medical condition, we use the diagnostic criteria for that disorder.

Q: Do you have an ongoing doctor/patient relationship with the patients you diagnose, including regular follow-up visits?

A: Yes. We consider the follow-up of our patients one of our most important functions. Problems change over time and families need help in management. We try to emphasize anticipatory guidance where possible. This allows us to teach management to parents before the child has a problem. This of course works best for common conditions.

Q: Do you refer your patients to another medical or mental health professional for ongoing medical care and treatment?

A: Yes. We have a child psychologist and a child psychiatrist as a part of our group. Many patients are managed by them independently of the rest of the team.

Q: What kind of long-term follow up

would you like to see for those with FAS?

A: We feel that at least an annual visit is required. FASD is a complex disorder and management at age three differs from management at age seventeen. For the most complex patients, we may need to see them 4-6 times a year. We believe this improves outcome, reduces secondary or preventable conditions and helps the rest of the family or care providers.

Q: What is your dream for the future of diagnosing this disability?

A: FAS - We hope to see widespread use of our screening system to identify people at high risk who would then be referred to a local provider for diagnosis. We have developed a system that pediatricians, child psychiatrists, child neurologists and others can use to diagnose most affected patients. We do not feel that most patients need referral to a specialty clinic for a diagnosis of FASD. For example, pediatricians manage many complex disorders with great expertise. FASD is a similar problem and we believe most patients with FASD need management close to home and can be managed by their local doctors. This makes the task of getting the ancillary services needed easier as well.

ARBD - This is a much neglected area and needs considerable attention. Birth defects are a common manifestation of prenatal alcohol exposure and ARBD needs increased attention as a potential etiology for many types of birth defects. Prenatal alcohol exposure also needs to be considered in patients with other syndromes. I believe prenatal alcohol exposure very likely increases the severity of these disorders and may add to the overall picture of birth defects.

ARND - That psychiatrists and psychologists will begin to make the diagnosis. They serve patients who are at the highest risk for this condition. We feel they have the expertise to make the diagnosis and treat the patients quite well. We hope the professional organizations for these disciplines will increase both their in-service training and the pre-service training. Adding questions about FASD on the licensing exams would be a great start in promoting coverage of FASD in the training programs. ♥

For more extensive and practical information, see Dr. Burd's website: www.online-clinic.com and click on introduction under fetal alcohol syndrome.

Paul Connor, PhD

Clinical Director, Fetal Alcohol and Drug Unit, Adult Neuropsychological Evaluation Clinic, University of Washington Medical Center, Seattle

Paul Connor graduated from Brigham Young University with a PhD in clinical psychology and a specialization in neuropsychology; his internship was spent in Detroit, Michigan in the Henry Ford Health System. While seeking a post-doctoral fellowship at the University of Washington (UW), he was advised to talk to Ann Streissguth about the neuropsychological consequences of fetal alcohol exposure. After he met with her, Paul says he was curious about what his textbooks had contained about fetal alcohol exposure, so he went back to check. He says, "In all my textbooks there was one paragraph on FAS."

Q: How long have you been in the field?

A: I began working at UW doing research with Ann Streissguth in 1995 near the end of the CDC Secondary Disabilities project. I was a Post Doctoral Fellow and Project Director of her longitudinal study. Later we got a grant to do neuropsychological testing and brain imaging to measure regions of the brain of affected individuals. We tried to identify common behaviors of affected individuals and match them to specific neurological damage identified through MRI imaging to find brain-behavior relationships.

Q: Why develop this research model?

A: We realized that although experienced clinicians have been diagnosing Fetal Alcohol Syndrome for over 30 years, the rest of the spectrum of fetal alcohol damage has not been classified effectively. So our proposal was to identify neuroanatomical structures that might supply useful discriminators of prenatal brain damage from alcohol.

Q: What did you discover?

A: The corpus callosum is a band of fibers that connects the two hemispheres of the brain and helps us integrate information gathered from each half so we can understand all the factors in our environment and have the information we need to make well-grounded, logical decisions. If the corpus callosum doesn't develop properly—e.g., is underdeveloped, missing all together, or even overdeveloped (as it is in some people with FAS)—that can dramatically effect their judgment and reasoning abilities. We found

that there are striking differences between controls and people who were exposed to alcohol prenatally in the statistical distributions of the shapes of the corpus callosum. FAS and FAE subjects had corpus callosa that were either too thick or too thin when compared with controls. We also found that in those with callosa that were too thin, they had deficits in motor coordination, while those with callosa that were too thick, had deficits in tasks involving problem solving and logical reasoning (executive functions). We learned that statistical analysis of brain shape is a powerful new source of information relevant to FASD. We also learned that patients with FAS and FAE do not differ in these brain shape features, but both differ from the corpus callosum shape in unexposed individuals.

Q: How has the retirement of Ann Streissguth affected your work?

A: When Ann decided to retire we realized that no one person could take her place, so the leadership of the Fetal Alcohol and Drug Unit was divided between three directors. Dr. Therese Grant is now the Director of the Fetal Alcohol and Drug Unit, which we call FADU. Dr. Fred Bookstein is the Scientific Director of Research and my role is Clinical Director. My work builds on our neuroanatomy and neuropsychology study. We have been doing work on a functional MRI (fMRI) study in individuals with FAS and FAE. This study demonstrated abnormalities in the functional activity of the brain due to prenatal alcohol exposure. Subjects with FAS, FAE and matched controls were given a series of neuropsychological tests spanning the functions of mathematics, attention, motor coordination and executive function while a special type of MRI is being conducted. Functional MRI (fMRI) measures local variations in the ratio between oxygenated and deoxygenated blood. Our initial analyses indicate that there is a difference in the patterns of brain activation between exposed patients and controls on the pattern and extent of activation of brain regions during these tasks. Like much of our previous work, there was really no significant differences between FAS and FAE in these patterns of activation.

Q: Which articles would help us learn more about your research in this area?

A: There are at least three papers that discuss our neuroimaging studies:

◆ The earliest one is an article published by *Teratology* in 2001 titled, "Geometric Mor-

phometrics of Corpus Callosum and Subcortical Structures in the Fetal-Alcohol-Affected Brain." Authors are Fred L. Bookstein, Paul D. Sampson, Ann P. Streissguth and Paul D. Connor.

◆ In 2002, *The Anatomical Record* published, "Midline Corpus Callosum is a Neuroanatomical Focus of Fetal Alcohol Damage." Authors are Fred L. Bookstein, Paul D. Sampson, Paul D. Connor and Ann P. Streissguth.

◆ In 2002, *NeuroImage*, "Corpus Callosum Shape and Neuropsychological Deficits in Adult Males with Heavy Fetal Alcohol Exposure." Authors are Fred L. Bookstein, Ann P. Streissguth, Paul D. Sampson, Paul D. Connor and Helen M. Barr.

Q: Why does your clinic focus on adults and what is your diagnostic process?

A: People with suspected prenatal alcohol exposure often are not formally evaluated for FASD, especially adults. A practitioner may have never linked their patient's cognitive and behavioral problems with the possibility that these deficits may be related to damage that occurred at the very earliest ages of development. This is what we hope to do with this clinic--make an appropriate prenatal alcohol-related diagnosis in these adults who may have slipped through the cracks as children and adolescents. A comprehensive neuropsychological assessment can determine if a person has cognitive and/or functional problems associated with prenatal alcohol exposure. If so, help is available to assist with treatment planning, and to make appropriate referrals for services that can address the patient's cognitive and functional needs, including referrals for full FAS diagnostic services. We offer adults (18 & over) a comprehensive neuropsychological evaluation designed to assess cognitive function, mental health status, and adaptive behavior among people exposed to high levels of alcohol prenatally. The evaluation combines a clinical interview, neuropsychological testing, and a review of previous psychological or psychiatric records. The evaluation involves two clinic visits: an assessment and a reporting conference approximately two weeks later. Referral to community resources and consultation with current providers will occur as needed. We do not offer ongoing psychotherapy or case management; however, we are available for follow-up consultation. Anyone wanting to request an evaluation can call Dr. Connor or Dr. Huggins at (206) 543-7155. ©

Alan Unis...

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on testing agents in children and adolescents with early-onset psychopathology, I was ready to pursue a fresh start toward helping children. New protocols needed to be developed for caring for affected children and I just did not see that happening, so I decided to make the change.

Q: Why do you think academic disciplines (for example, mental health) at universities do not seem to be making progress toward preparing their workforces to address FASD?

A: In my opinion it is because researchers must focus their attention on very narrow questions in order to come up with entirely new discoveries. The grant support that investigators need to advance their careers requires them to study such narrowly defined questions that are answerable in discretely designed experiments. Clinical service development has not been a particular emphasis of academic centers whose funding base is driven by getting research grants that answer cutting edge questions and there are no clear mechanisms for turning answers to such questions into therapeutic advances.

Q: How do you see that intellectual climate being changed?

A: For one thing, we must no longer discount the observations of parents. We need true partnerships to maximize both the observations and the theories of helping these children/youth.

Q: What do you see as your strengths?

A: I had the benefit of a pediatric internship, which provided me with a basis for knowing about normal and abnormal child development especially in the context of diagnoseable medical conditions. I also had the benefit of extensive collaborations with other developmental neuroscientists and psychologists who understood how abnormal brain development translates into abnormal psychological and behavioral development. Finally, I have had the benefit of treating enough children and adolescents with psychotropic agents to gain some understanding of the potential benefits, risks and limitations of such treatment.

Q: Describe your method of care for us.

A: First we try to complete a comprehensive diagnostic evaluation. This may include an EEG, neuroimaging studies and/or psychological testing. Next we arrive at a formulation, which is an over-arching expla-

nation of how I might understand a child's or adolescent's presentation. I try to take into account the predisposing characteristics and the precipitating events, as well as the factors that are keeping the patient stuck in a maladaptive pattern of behaviors. But I also want to identify the patient's potential or strengths. This formulation includes my working theories as to how I might impact change, using medications in the context of other rehabilitative therapies. The formulation provides the framework for a treatment plan.

When considering medications, I begin with those that have the most evidence for impacting the most problematic behaviors. After the patient is more comfortable and calm, we look at the other rehabilitative therapies that might help the child.

I always keep in mind that there is no uniform, systematic approach that will help all those with FAS/FAE because each one is unique and each situation must be identified and addressed. During this process, we continually work with the families to get some idea of what they think might work according to their expertise in caring for their children. This process may need to be repeated continually throughout childhood. ♥

To learn more about the psychiatric care of children and youth at Sacred Heart Medical Center see Dr. Unis' website: www.shmc.org/index.php/page/274.

LIFE in the FAS LANE

Claudia Barker, Texas ♦ Summer 2005

I don't think I've ever been prouder of my daughter, Anne Marie. We finished up the week of VBS with the closing program tonight. She was a "crew leader." The staff gave her the smallest crew (only 1-3 kids each day), but she did great and even, of her own inspiration, made necklaces for her kids and passed them out today.

Earlier in the week, when she saw that the lines for handwashing before snack were so long, she took a bottle of waterless hand sanitizer for her kids—she thought of that herself. She also took her own trash bag each day, so that her kids wouldn't leave messes, and some extra pens because there weren't

enough available.

Tonight, she got up on stage when they asked for the crew leaders to come up, and she passed out the perfect attendance gift to the one kid she had who had perfect attendance—in front of all those people!

She got herself up on time every day and got herself dressed in the safari clothes that the crew leaders wore, she made her own breakfast and took her [medication] without being told. She tolerated the loud music and dancing (we're talking about a room full of 100+ kids!), she got her kids to their stations on time, helped them make their crafts and snacks—and didn't eat the snacks herself!

After the program, the director came to us and told us what a wonderful job she had done, that she hadn't lost her temper with her kids as some of the crew leaders had done (and as he had done, himself, actually), and that even though he had been reluctant to let her be a crew leader, she had done better than some of the older kids.

Then Anne Marie took her dad, Kelly and me on a tour, explaining what the children did at the various "stations." As we were about to go, a little boy came up to her and told her he couldn't find his big brother, and she told us to wait right there, while she took him to look for his brother.

I'm really proud of this girl today. Amazing, for a kid who was never supposed to walk or talk! You know, what I really want for each of my kids is for them to be useful to other people in some way. Tonight was my dream come true. VBS was better because Anne Marie WAS THERE! I had to put a lot of effort into it—educating the director beforehand about Anne Marie's disabilities, talking her through what was going to happen the next day every night, and bringing her straight home after each day so that she could sleep and recover, but SHE DID IT!!!

When we got home, we discovered that fire ants had invaded our baby chicken cage out back and several baby chicks had been badly bitten. She brought the chicks in and bathed and dried them very carefully and put them all safely back in a box in the classroom until we can figure out what to do with them tomorrow. I'm thinking, "WHOA! Is this my kid?"

I'm going to savor this, because tomorrow she could be back to making up stories about our family's recreational use of cocaine and heroin, or turning into a whimpering ball of a child when the nurse wants to draw blood. But for now, this is sweet success! ♥

Progress Report:

Transforming the Washington State Mental Health System

The legislative session of 2005 was a *most excellent adventure* for those of us who love and care for family members who have mental health conditions because the Washington State legislature passed the following bills:

- ◆ Engrossed Second Substitute House Bill 1290, which will profoundly transform the way mental health services are delivered in the community;
- ◆ Engrossed Second Substitute Senate Bill 5763 that addresses treatment of substance abuse in persons who have mental health disorders;
- ◆ House Bill 1154 which grants insurance coverage parity for mental health;
- ◆ Appropriation of nearly \$82 million additional non-Medicaid, state-only dollars for mental health services in the state's 2005-2007 biennial budget.

According to Governor Christine Gregoire, "These triumphs come on the heels of much work by the Joint Legislative and Executive Task Force on Mental Health Services and Financing. At this time, citizens, policy makers and service agencies in the state of Washington are poised to undertake the next step in reforming our state's mental health system." The next step to which she was referring was an application by her office for assistance through a federal Mental Health Transformation State Incentive Grant (MHT SIG) from the Substance Abuse and Mental Health Services Administration (SAMHSA). But the good news didn't stop with the application. In November 2005 Governor Gregoire announced that the state of Washington was awarded one of only seven grants in the United States for this initiative.

Ken Stark, Director of the Washington State Division of Alcohol and Substance Abuse for almost eighteen years, was reassigned by Governor Gregoire and introduced at the initial meeting in December as Project Director for the mental health grant. Ken is a people person and negotiator of the highest caliber and we advocates at Washington PAVE and the FAS Family Resource Institute have high hopes for positive outcomes of this effort.

A vision statement from the Governor

was distributed at the first meeting and read, in part, "It is our vision that all people in the state of Washington who experience mental health challenges will lead happy, productive and fulfilling lives, free of stigma—in a safe and least restrictive environment. This initiative will fundamentally change the way mental health care is provided and the way mental illness is perceived. **State and local government will be accountable to consumers and families for cultural competence and service outcomes.** The new mental health system will be consumer-driven; mental health will be understood as an essential element of overall health, and as a condition from which people can and do recover."

THE POWER OF YOUR STORY

As you might imagine, these developments are very encouraging to us and we want you to be a part of the process. In collaboration with Washington PAVE and other mental health and disability advocacy organizations around the state, FAS*FRI is hosting a series of grassroots meetings for individuals with mental health conditions and their families to come together and discuss their hopes and dreams for the future of mental health services in the state of Washington. There is much power in relating our stories—what we have experienced and what can be learned from it.

Washington State is seeking testimony from its citizens on these questions about mental health services:

1. What works?
2. What doesn't work?
3. What would your ideal mental health system look like?
4. How will you know the system has improved?

Please join us. We all want a more responsive system for our children and families, so we must take this opportunity to make sure our voices are heard. You can get involved by calling Vicky McKinney at (800) 999-3429 or (360) 985-7317 or by e-mailing her at Vicky@fetalalcohol syndrome.org.

If not you, who will speak for the children? ♥

FAS*FRI's Three Newest Publications

Nurture: The Essence of Intervention

This beautiful, gentle book is a showcase of over 60 affected individuals of all ages and races. Each individual's personality is happily expressed in a collage of photographs, accompanied by a brief review of medical and mental health history as well as challenges and strengths. This photo book of individuals disabled by prenatal alcohol exposure is the first and only one available on the market. It's a "must read" for any professional who is serious about recognizing and helping people with FASD. Cost: \$35 U.S.

Fetal Alcohol Syndrome & ME

This 2-booklet series was designed to encourage and build self esteem in children who have disabilities from prenatal alcohol exposure. Their cheerful educational message is rooted in the common behavior pattern unique to FASD, with a strong focus on the endearing qualities which make affected kids so loveable. The words are phrased in the gentle language of childhood and expressed by a happy little cartoon elephant. The two booklets are entitled:

- ☐ "What's a Diagnosis?: Identifying a Disability" *and*
 - ☐ "Free to Just Be ME: Understanding My Strengths and Weaknesses"
- Cost: \$3.00 U.S. per set

Prevention/Public Awareness Poster

This poster, featuring individuals from the photo book, has a very dramatic impact and is becoming a popular educational tool. Available in two sizes:

- ☐ 8 1/2" x 11" Cost: \$3.00 U.S.
- ☐ 24" x 28" Cost: \$5.00 U.S.

All prices are **U.S. funds only** and include postage and handling.

Vicky@fetalalcoholsyndrome.org or
(800) 999-3429

Send check or money order payable to:
FAS*FRI Publications
P.O. Box 2525
Lynnwood, WA 98036

Colleen Morris...

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that you diagnosed during your career?

A: 650.

Q: How many patients do you see on a monthly basis?

A: 8.

Q: Where do your referrals typically come from?

A: Division of Family Services (foster care), Early Intervention services, school district, Nevada PEP (parent support group), psychiatrists, pediatricians, social workers, teachers, nurses.

Q: How many of these patients are coming to you because they or their referring agent believe they have FASD?

A: 30%.

Q: What percentage of your patients actually receive a diagnosis related to prenatal alcohol exposure?

A: From 1988 to 2005, 650 were diagnosed with FAS; another 600 had prenatal exposure to alcohol and drugs, but did not get a

diagnosis in the FAS spectrum on the first visit. However, we changed diagnostic criteria in 1996 (following IOM report), and changed again in 2004 (following CDC guidelines).

Q: What diagnostic criteria do you use?

A: We now use the CDC guidelines for FAS diagnosis. For the rest of the spectrum: Partial FAS must have either growth failure OR neurologic findings AND must have one typical facial feature. ARND does not have to have FAS physical findings, but must have the FAS neurodevelopmental/behavioral problems.

Q: Do you primarily focus on the facial features of FAS?

A: Not any more.

Q: Do you diagnose other conditions (such as disabilities/mental health disorders) caused by prenatal alcohol exposure in addition to FAS?

A: Yes, our developmental/behavioral pediatrician does.

Q: What diagnostic criteria do you use for these conditions?

A: DSM IV.

Q: Do you refer your patients to another medical or mental health professional for co-occurring conditions?

A: Yes, we refer to therapists, including mental health therapists in the community.

Q: What kind of long term follow up would you like to see for those with FAS?

A: I would like to see a mentor/advocate/caseworker assigned to each person throughout the life span.

Q: What is your dream for the future of diagnosing FAS?

A: That well-accepted criteria will be utilized to diagnose partial FAS, just as it is for FAS, and that people in health care, mental health and early intervention will learn to recognize it.

ARBD - That genetic predisposing factors will be identified and can be used for counseling and therapy.

ARND - That educators and psychologists and other professionals will first believe that it exists and then be able to recognize it. That the criteria will be published in the [next revision of the] DSM. ♥

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