

FAS TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

FASD: Diagnosing the Spectrum - Part II

Jocie DeVries

Life has been interesting in my little corner of the world lately—not that it's ever been dull—but sometimes life just surprises you. On the one hand, I have been preoccupied with reading and analyzing the research of the different scientists that we've featured in the winter and now spring issues of FAS Times. On the other hand, FAS*FRI's overall mentoring and advocacy has recently spotlighted a new meaning of success that I hadn't noticed before and it is striking.

A lot of my time, and my colleagues' time, is spent trying to help parents keep their children with FASD from falling through the cracks in our social service systems. This can be agony for the affected children, their siblings and parents. But now that we have been doing this for fifteen years, the kids of some of the first families we worked with have grown up and have turned to us for help as trusted mentors. As a result, we are sharing with a succeeding generation our basic intervention strategies which can bring a measure of stability and happiness. Sometimes life is not so bad on the other side of childhood. Sometimes it's success redefined.

I think of one not-so-young man, whom we have struggled so hard to help. He is one who fell through the cracks early and often. As a young adult he spent a lot of time living on the street and doing drugs but was eventually rescued by some young men in a faith-based recovery plan, which is where we met him. There indeed must be a special place in heaven for the men and women who have this type of ministry. Through their own youth and naiveté, these men expected sobriety, recovery and maturity in this man which would, of course, result in a disciple who would be able to return the favor and mentor other people who live on the street. Well, that's a good idea; but when it comes to being born with neurological brain damage from generations of fetal alcohol exposure, it often doesn't work out that way. In his case, success cannot be defined by whether or not he is able to live independently. Success is defined by the fact that, once rescued from the street, he doesn't feel isolated, he does have a social peer group, and he has a safe place to sleep.

Our advocacy boiled down to letting him know that no matter how far down through the culture he fell, we were not giving up on him and we expected his church family to feel the same way. We expressed our goal to those who were ready to throw him to the wind because he was never able to meet their expectations—to become a disciple and mentor. In essence we taught him that he was a member of God's family and that God is in the business of loving and supporting people who trust Him and that the Creator God is trustworthy. Therefore we encouraged the church officials in his life to look beyond Plan A (becoming independent)—when he is homeless, take him in as long as he is cooperative, but even more importantly give him a safe place to sleep (unobtrusively in the parking lot) when he *seemingly* refuses to cooperate. The success has thrilled everybody. Even though he still sleeps in his car occasionally, he attends church meetings three or four times a week (including regular attendance at their Alcoholics Anonymous meetings), sees a church counselor regularly, attends an emotional recovery group, and participates in every extra curricular activity that any group sponsors in the church building. He is the most eloquent man of prayer you can imagine because he has a happy, grateful heart and has had lots of practice talking to God. He may live in the shadows of our culture, but he is working toward a college degree in computer technology.

In this issue of FAS Times you will find another beautiful success story written by one of our Board of Directors, Ken Dunning. Being a family-run organization, about 80% of our board members are either parents of children with FASD or affected adults; but Ken is a child and family mental health therapist. One of the strongest motivating factors in his life has been trying to understand the complex relationship between himself and his brother, Greg. Be sure and read on page 10 the fascinating story of another life, lived successfully, even after falling through the cracks.

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You might ask, just what does *that* mean? It means that Greg's life did not follow Plan A. Upon examining the course of his life, most people might say that it was a disaster, but not his brother Ken. Ken looked deeper into the soul (which of course is what makes him a good therapist) and found all the good things to celebrate in Greg's life. Ken didn't have blinders on or live in denial about Greg's egocentric (and sometimes illegal) behavior; he just observed, shook his head in awe at how Greg always seemed to land cheerfully on his feet, and learned to appreciate the genuine innocence of Greg's nature.

When I thought about it, I found myself asking: Isn't that what we all struggle to learn? As you read and contemplate this issue of FAS Times, I think you will see, as I did, that the motivating factor behind the scientific work of all the doctors and researchers that we have featured is that same struggle: What makes people with this disability tick? How can it be that they can be so mischievous and maddening and yet so darn cute and lovable at the same time? It's not one or the other; it's both sides of the same person—the sweet innocence and the self-centeredness.

That's the mystery of FAS. The scientific discoveries are absolutely fascinating. But they are even more intriguing when they bridge the gap between the theoretical and the practical—when they can identify and explain the very real people behind the disability. ♥

**Kenneth Lyons
Jones, MD**
Chief, Division of
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Department of Pediatrics
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It is important to emphasize that alcohol is primarily a behavioral teratogen. Although there is a broad spectrum of defects associated with prenatal alcohol exposure, the developing structure most sensitive to alcohol is the brain, and the resulting neurobehavioral abnormalities have the most profound and lasting consequences for affected individuals. [emphasis ours] Thus, although a distinct neurobehavioral phenotype, which is comparable to the structural features that are characteristic of prenatal alcohol exposure, has not yet been identified, the classification of affected children in this study, based on measures of cognitive performance and development, seems most relevant from a public health perspective.

Dr. Ken Jones
The Role of Genetic Susceptibility for Maternal Alcohol Metabolism in Determining Pregnancy Outcomes
Editorial in the Journal of Pediatrics,
January 2006

According to the Collective Family Experience, which FAS*FRI started gathering from our first parent survey in March 1991, testimony such as this statement by Dr. Jones is the single most important factor that keeps us parents from giving up and helps us preserve the bond of nurture in our relationships with our affected children. Such declarations by noted empirical researchers provide us a secure anchor for understanding FASD and a foundation on which we can develop strategies to keep our children and others safe from their innocent but unpredictable behavior.

When Dr. Jones gave his lecture to the Teratology Society in 2002, he stated the following two goals for his speech:

1. Set forth the most important scientific issues related to the recognition of FAS and
2. Put the scientific issues related to this disorder into the context of two individuals, Josef Warkany and David Smith. Their vision of science went far beyond recog-

niton to embrace the reality that with recognition comes responsibility. The responsibility is to take one's observations and scientific achievements beyond the laboratory or the bedside into the mainstream of human existence, to educate and in some situations to involve oneself in discussion of public policy.

"Dr. Josef Warkany was born 100 years ago in Vienna, Austria. In 1932 he came to America and spent his career at the University of Cincinnati. In 1953 he took the position of Professor of Research Pediatrics. Between 1966 and 1976, Dr. Warkany served as Director of Mental Retardation Research at the Children's Hospital Research Foundation. In part, his work focused on experimental teratology, recognizing the effect of maternal dietary deficiencies on fetal development. He was deeply committed to developing public policy that would protect the health of unborn children and his life's work demonstrated a profound responsibility to society.

"Dr. David Smith, born in 1927 in Oakland, California, received his medical degree from Johns Hopkins; after 3 years of pediatric residency training, he completed a fellowship in pediatric endocrinology. He joined the Department of Pediatrics at the University of Wisconsin and over the years spent as an endocrinologist at the university, became intrigued by the large numbers of children referred to him for short stature who had other structural defects but lacked any endocrinologic problem. As was typical with his nature, he was determined to understand those problems better and thus was born the field of dysmorphology. Later he spent a year studying human embryology with Dr. Gian Tonderry. Afterwards, he went to the University of Washington where he collaborated with other researchers in the Teratology Society to develop one of the foremost programs in dysmorphology, teratology and human embryology in the United States. Although David Smith was dedicated to his work, eminently talented and intellectually curious, he was first of all a pediatrician who felt a profound responsibility to care for children with birth defects and to educate the public about the causes of birth defects. Anyone who knew him could sense the deep responsibility that he felt to instill in young physicians who would follow him the same excitement and urgency that he felt about the field.

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Save the Date!
October 6 & 7, 2006
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Who's Affected and
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Target Participants: Educators,
Medical Doctors, Mental Health
Professionals and Parents

Conference sponsored by
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Phil May, PhD

Professor of Sociology;
Professor of Family and
Community Medicine,
University of New Mexico

Dr. May has been solely a researcher and prevention specialist since the beginning of his career in FASD about 26 years ago. He is the Principal Investigator of the distinguished research team of Hoyme, Robinson, Kalberg and many others. Their research collaboration includes patients in the Native American population of the Northern Plains, South Africa and Italy. When asked what it was that originally brought him into the field of FAS, Dr. May said that it was in 1980 when he was studying the epidemiology of FAS for the Indian Health Service.

Q: What is your primary area of research?

A: Prevention, epidemiology and maternal risk factors.

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

A: My projects have diagnosed over 450 individuals.

Q: Where do your referrals typically come from?

A: Local communities, schools and local providers.

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

A: It varies from project to project. All of our work in the Plains and New Mexico is from referrals, but in South Africa and Italy, we do active case ascertainment in the schools.

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

A: 2 - 12% depending on the project and the population studied.

Q: What diagnostic criteria do you use?

A: Revised Institutes Of Medicine (IOM) criteria (Hoyme, et al, 2005) I was a member of the 1996 IOM committee on FAS and I believe that the criteria defined by the IOM committee are extremely useful.

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

A: No, we focus on extensive examination of three domains: 1) physical growth and

dysmorphology, 2) intelligence and behavior, and 3) maternal history of risk factors.

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

A: Yes, our dysmorphologists, diagnosticians, and psychologists do.

Q: If yes, what do you call these diagnoses/conditions?

A: Partial FAS, ARBD and ARND.

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

A: IOM criteria from the 1996 report.

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

A: It depends on the research project, some yes and some no.

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

A: Yes, when warranted.

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

A: Educational interventions are particularly useful for all children with FASD.

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

A: That people use the IOM criteria which ensures that all diagnoses are made only after the dysmorphology, maternal risk and neuropsychology are assessed and weighted according to the Revised IOM Criteria.

Dr. May has been the Principal Investigator for many of the studies funded by the National Institute of Alcohol Abuse and Alcoholism (NIAAA). His first work (which was with Karen Hymbaugh, now a scientist at the Centers for Disease Control and Prevention) began as a pilot study on the incidence of fetal alcohol syndrome among American Indian people. The results were published in 1982 in the scientific journal, *Alcohol Health and Research World*. **The article describes a comprehensive program designed to study and prevent FAS among Indians in the Southwest United States.** The project featured clinical diagnosis and treatment, the development of an FAS training and education curriculum for related staff

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Fred Bookstein, PhD

Professor of Statistics, Professor of
Psychiatry & Behavioral Sciences;
Scientific Director,
Fetal Alcohol & Drug Unit (FADU)
University of Washington

Dr. Bookstein recently retired from the University of Michigan as a Research Professor in the Institute of Gerontology, although he is still serving as Professor of Anthropology at the University of Vienna. He has spent more than twenty years as a major force in developing the data acquisition software and data analysis methods that are used in the corpus callosum studies with Drs. Sampson and Streissguth at the University of Washington. And his work in the U.S. is not finished.

On November 11th, 2005, during her elegant retirement reception, Dr. Ann Streissguth welcomed Dr. Bookstein to his new position as the Scientific Director of the Fetal Alcohol and Drug Unit (FADU). FAS*FRI is delighted have Dr. Bookstein in Seattle because he is working on some of the most fascinating studies on fetal alcohol exposure that have ever been done. The results of his research (and other MRI studies at various universities) are providing a practical, logical basis from which the common behavior pattern of FAS and ARND can be explained and understood. We are also hopeful that the results of these studies will eventually be standardized into medical diagnostic criteria for ARND.

The first research project to which we wanted to introduce you was written by Dr. Bookstein with Ann P. Streissguth, Paul D. Sampson, Paul D. Connor and Helen M. Barr. The topic, *Corpus Callosum Shape and Neuropsychological Deficits in Adult Males with Heavy Fetal Alcohol Exposure* was published in *NeuroImage* in 2002. The abstract explains the significance of this study: "Persons with brain damage consequent to prenatal alcohol exposure have typically been diagnosed with either fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE), depending on facial features. There is great variability of behavioral deficits within these groups. We sought to combine neuroanatomical measures with neurocognitive and neuromotor measures in criteria of greater sensitivity over the variety of consequences of alcohol exposure. To this end, midline curves of the corpus callosum were carefully

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Fred Bookstein...

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digitized in three dimensions from magnetic resonance (MR) scans of 15 adult males diagnosed with FAS, 15 with FAE, and 15 who were unexposed and clinically normal. From 5 hours of neuropsychological testing we extracted 260 scores and ratings pertaining to attention, memory, executive function, fine and gross motor performance, and intelligence. Callosal midline shape was analyzed by new morphometric methods and the relation of shape to behavior. The FAS and FAE subgroups have strikingly more variability of callosal shape than the normal subjects. With the excess shape variation are associated two different profiles of behavioral deficit unrelated to full-scale IQ or to the FAS/FAE distinction within the exposed subgroups. **A relatively thick callosum is associated with a pattern of deficit in executive function and one that is relatively thin, with a deficit in motor function.** The two combine in very promising bipolar discrimination in callosal form for prognosis of neuropsychological deficits in this frequently encountered birth defect.”

The second research article that we want to bring to your attention was also written by Dr. Bookstein with Paul D. Sampson, Paul D. Connor and Ann P. Streissguth. *Midline Corpus Callosum is a Neuroanatomical Focus of Fetal Alcohol Damage* was published in *The Anatomical Record* in 2002. The abstract explains the significance of this follow-up corpus callosum study which included 15 adolescent males (aged 14 through 17), 15 adult males, 15 adolescent females, and 15 adult females: “Prenatal exposure to high levels of alcohol often induces birth defects that combine morphological stigmata with neurological or neuropsychological deficits. But it has proved problematic to diagnose these syndromes in adolescents and adults in whom the morphological signs are absent or attenuated, the behavioral deficits nonspecific, and the exposure history often difficult to reconstruct. Localizing the associated brain abnormalities might circumvent most of these difficulties. To this end, three-dimensional locations were recorded for 67 homologous points on or near the corpus callosum in MR brain images from 60 adolescents and adults who were normal, 60 diagnosed with fetal alcohol syndrome and 60 diagnosed with fetal alcohol effects. We combined the standard statistical approach

to this type of geometric data, Procrustes analysis, with a multivariate strategy focusing on differences in variability. In this data set, the shape of the corpus callosum and its vicinity proves systematically much more variable in the alcohol-affected brains than in those of the normal subjects. From this excess variability follows a promising classification rule, having both high sensitivity (100 out of 117) and specificity (49 out of 60) in this sample. The discrimination uses four landmark points and two summary scores of callosal outline shape. **The information from the corpus callosum and vicinity, as viewed in MR brain images of full grown subjects may serve as a permanent record of the prenatal effects of alcohol** even in patients who are first suspected of these syndromes relatively late in life or who lack the facial signs of prenatal alcohol damage. The statistical pattern underlying the callosal diagnosis also leads to speculations on mechanisms of the prenatal damage.”

[Update] Dr. Bookstein and his colleagues’ most recent scientific finding reflects the team’s continuing assessments of these original MR studies that revealed patterns of corpus callosum damage. The most recent data is showing an *even more striking pattern of damage in the cerebellum* of those same exposed subjects. An abstract is not yet available, but the results have been released through a presentation by Dr. Bookstein recently given in Alaska. The cerebellum (or “little brain”) is a structure below and to the rear of the cortex that has been known for a longtime to be too small, on the average, in the brains of FASD patients. The FADU team showed that there is a wide size range in the cerebellums of adolescents/adults with FASD. Although the FASD cerebellums that seem to be within the normal size range have the same average shape as the normal cerebellum, nearly four-fifths of the patients in their study of 60 adults with FASD can be characterized as having abnormally small cerebellums just by measuring the size of the cerebellum in a sufficiently careful way. The well-known variability in motor function problems that characterizes the FASD patient population might in this way trace back directly to variability in the extent to which the cerebellum itself was specifically damaged by the alcohol exposure.

The third research article, also primarily written by Dr. Bookstein with Paul D.

Sampson, Kristi D. Covell, Helen M. Barr, Christine A. Gleason, Raymond W. Sze, Jenny A. McBroom and Ann P. Streissguth, is entitled, *Preliminary evidence that prenatal alcohol damage may be visible in averaged ultrasound images of the neonatal human corpus callosum*. It was published in the December 2005 issue of the journal, *Alcohol*. The abstract reads: “Brain damage consequent to prenatal alcohol exposure can be detected by measurements of the corpus callosum in the midline MR brain image in adolescents and adults. The present article extends this finding into the neonatal period, when the power of detection to ameliorate the quality of the child’s future life is greatest. The midline corpus callosum of the very young infant can be located reliably in multiple frames of clinical transfontanelle ultrasound. A sample of 18 children was studied, aged 17 weeks or less, 7 of whom were exposed to high levels of alcohol prenatally and 11 of whom were not exposed or... minimally exposed. The midline callosum of each child was imaged up to 50 times by a standard clinical device, and coplanar subsets of these series were averaged with reference to fiducial image structures. On each average image, four semilandmark points were set and their configuration quantified by standard landmark methods. The angle between the terminal bulb of splenium and the long axis of the callosal outline classifies four of the seven exposed infants as different from all 11 of the unexposed infants. **This simple angle measurement upon averaged ultrasound images of the human neonatal midline corpus callosum is perhaps a version of the long-sought ‘biomarker of prenatal alcohol damage’** and may be able to discriminate baby brains affected by prenatal alcohol exposure from those that were unaffected.” The FADU team hopes to integrate neonatal imaging of the cerebellum into this work, to see if that measurement proves feasible at ages as early as the corpus callosum measurement turned out to be.

Besides his many research projects, Dr. Bookstein has also immersed himself in the task of bringing scientific research into the arena of public policy change. We are very thankful for this because his areas of concern are much the same as those we have at FAS*FRI—to bring to light scientific data about the neurological damage of those with FAS/ARND who up until now have been trapped in the revolving doors of our jails, prisons and mental health institutions. ♥

Luther K. Robinson, MD

Associate Professor of Pediatrics;
Director, Dysmorphology and
Clinical Genetics,
School of Medicine and
Biomedical Sciences,
State University of New York at
Buffalo

When he was asked how he got interested in Fetal Alcohol Syndrome, Dr. Robinson answered with a twinkle in his eye, “Well, it was quite by chance really. While I was doing my pediatric residency at San Diego State University, I chose an elective by professor Kenneth Lyons Jones.” Dr. Robinson says of that experience, “Ken’s enthusiasm for his work to prevent birth defects from fetal alcohol exposure was so contagious that I refocused my career—instead of going into pediatric medicine, I turned to dysmorphology.” My first faculty position was in the Department of Pediatrics at the University of Texas Medical School at Houston. But in 1987 I moved to the State University of New York at Buffalo where I still live and work today.

“I had always assumed that my practice would be about ‘barrettes and braids’ [young children]. But as I got more deeply involved with my patients, I began to note that in the science of birth defects every cell is encoded with that syndrome and this intrigued me. Gradually I started concentrating on other causes of birth defects such as thalidomide and my interest was kindled into working to prevent birth defects by finding out what causes them. My thoughts went something like this, ‘OK, can we really *prevent* Down syndrome other than by not getting pregnant in the first place?’ For me, that didn’t seem like a very good or practical choice. Then gradually, as the years went by, I began thinking more and more about Ken Jones’ work in preventing fetal alcohol syndrome. For one thing, it disturbed me that the scientific data indicated that there was a greater rate of FAS among African Americans than the general population and I began to wonder if that outcome was really what the data were showing. Having my curiosity so kindled eventually led me to the work I’m involved in today.

“My current work involves not only my clinical practice at the State University of

New York at Buffalo but includes basic fetal alcohol research in ethnic populations around the world with Ken Jones, Philip May, Gene Hoyme, Wendy Kalberg and others. We are working together to study the effects of fetal alcohol exposure in Russia, the Ukraine, Italy, Finland, South Africa, and among Native American and Alaska Native peoples. Now that I have been working with these colleagues for many years, I know that FAS is over-recognized in minority populations because when doctors want to do research they go where the kids are—and there are a lot of kids in clinics where poor folks come for medical care. The over-recognized FAS in minority populations happens because that’s where we’re collecting the data.

“The data from our most recent study is very interesting. It was published in September 2005 in the *Journal of Studies on Alcohol*. The topic, ‘Fetal Alcohol Syndrome Epidemiology in a South African Community: A Second Study of a Very High Prevalence Area,’ was not so much a study on the high rates of FAS in the Western Cape of Africa as it was on the fact that severe episodic drinking is the pattern of drinking that leads to FAS in low-SES [Socio-Economic Status] populations, and maybe in any population. The data that have been gathered summarizes a second active case ascertainment initiative that gives us the prevalence of FAS in the Western Cape Province of the Republic of South Africa. The project (funded by the National Institute on Alcohol Abuse and Alcoholism, the National Institute on Minority Health and Health Disparities and the Foundation for Alcohol Related Research of South Africa) follows an initial, comprehensive inquiry in 1997 that documented the highest rate of FAS ever reported, more than 40 per 1,000 and raised many issues regarding the exact conditions producing FAS in South Africa and generally in human populations. (Adnams, 2001; May, et al, 2000; Viljoen, et al, 2002)

These two studies were conducted in a collaborative project with the government of South Africa and are unique to the scientific inquiry on fetal alcohol exposure because it had all of the following factors:

- ◆ population based;
- ◆ agreement and full consent of the people in the community;
- ◆ a very high prevalence of FAS;

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Wendy O. Kalberg, MA, CED

Certified Ed. Diagnostician
University of New Mexico

Ms. Kalberg is a member of the distinguished diagnostic research team which includes Dr. Luther Robinson, Dr. Philip May and Dr. Eugene Hoyme (also featured in this issue). She has worked with this team for nine years.

When asked what originally brought her into the field of FAS, Ms. Kalberg stated, “My educational background is in disabilities of young children, from birth to age three. I then went on to study disabilities across the age span. I worked for 9 years at the University Affiliated Program (UAP) in New Mexico that targets its efforts at improving life for individuals with disabilities through policy development, improved evaluation and diagnosis, and training and technical assistance.”

Q: How long have you been in this field?

A: I have worked in the field of disability diagnosis and programming for 18 years, specifically focused on FAS for 9 years.

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

A: Both.

Q: What is your primary area of research?

A: Diagnostic criteria, prevention, and intervention. I am interested in a better quality of life for children who have been prenatally exposed to alcohol. It is my passion to work with other disciplines to better diagnose the full spectrum of effects in children who were exposed to alcohol prenatally and to create individual learning profiles for affected children so that they can receive meaningful educational programming that is tailored to the specific needs of the individual child.

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

A: We work as a multidisciplinary team in making the diagnosis. We have pediatric dysmorphologists who do the medical evaluations. I evaluate the children with regard to early developmental skills (when they are less than 4 years of age) and I do psychometric and neuropsychological testing with the older children. We also have

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Kenneth Jones...

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“Recognition of the Fetal Alcohol Syndrome was based on the evaluation of eight children born to alcoholic mothers who were initially diagnosed by Dr. Christie Ulleland, a pediatric resident at the University of Washington, and then followed by Dr. Shirley Anderson, Director of the Pediatric Outpatient Clinic at King County Hospital (Harborview Medical Center). On February 23, 1973, those eight children were evaluated by dysmorphologist Dr. David Smith and myself when I was his fellow. Four of the children had the unique pattern of malformation ultimately referred to as FAS. On that same day a search of Dr. Smith’s files revealed two more children with a similar pattern of malformation born to alcoholic mothers. During the next week two additional affected children were identified, one by me in Seattle and the other by Dr. Smith who was spending a week as a Visiting Professor in Akron, Ohio. Thus in a period of 2 weeks, a specific pattern of structural defects associated with growth and mental deficiency was recognized in eight children born from women who had abused alcohol.”

When Dr. Jones was asked how it felt when the significance of their discovery of the syndrome began to dawn on him, he replied, “I was totally stunned and I wondered how in the world physicians could have missed such a significant phenomena throughout human history. It also left me stunned when the paper we wrote was accepted by the scientific journal, *Lancet*, in two days and the editors thought it was such a significant discovery that they didn’t even send the article out for review.

“The next questions we had were: How common is this? Does every woman who drinks produce an affected child? But it wasn’t long until we found two more children in Seattle; one lived but one died and that was significant because doctors were able to do the first known autopsy on a child with the syndrome. Although that was an indescribable tragedy to the child and family, it did provide scientific data that there was severe neurological and neuropathological damage to affected children. That was where that brain slide came from that is so widely used in public awareness

campaigns even now.

“The next step of discovery for us was through a collaboration with the National Institute of Neurological Disease and Stroke. They had research data from following 55,000 children up through seven years of age. This data base was an incred-

Dr. Jones is the Principal Investigator for the OTIS* Research Studies. His research has focused on the clinical delineation of birth defects, mechanisms of normal and abnormal morphogenesis and the recognition of new human teratogens. The work on recognition of new human teratogens is primarily focused through CTIS Pregnancy Risk Information, a service which is funded by California.

Dr. Jones has authored over 400 publications in scientific journals as well as several books, and is the author of Smith’s *Recognizable Patterns of Human Malformation*. He is considered to be the father of Fetal Alcohol Syndrome (FAS) since he was one of two doctors at the University of Washington who first identified FAS in the United States in 1973.

As Chief of UCSD Medical Center’s Division of Dysmorphology/Teratology, Dr. Jones is in clinical service throughout the year, and trains fellows in dysmorphology. Teaching goes on virtually every day as he sees patients in clinics and serves as consultant on hospital inpatient services throughout San Diego County.

Dr. Jones is past president of the Western Society for Pediatric Research and president elect of the Teratology Society as well as the co-chair of the Scientific Working Group on Diagnostic Guidelines for Fetal Alcohol Syndrome, convened by the National Center of Birth Defects & Developmental Disabilities [in the Centers for Disease Control].

**Organization of Teratology
Information Specialists*

http://otispregnancy.org/otis_physicians.asp

ible find because these children had been through a battery of tests during their first seven years of life—testing vision, hearing, neurological responses—and all that data was in the computer. We received permission to search the data so we started looking for babies of chronic alcoholics.

“Ann Streissguth and I went to the National Institutes of Health and studied the charts. I was looking through the physical and medical histories and Ann was searching through all the neurological records. We found 23 other babies with the syndrome and 46 controls. Four of the babies had died but 19 had lived. As we struggled to understand the meaning of the data we found, we debated on the best way to determine the full spectrum of the disorder.

“We determined that to find the full spectrum of the disorder, we scientists would need to start documenting the child’s health and family history from the time of conception. That’s why I have so much admiration for the work of Ann Streissguth and Claire Coles because over time this is how we will get the data on the full spectrum of fetal alcohol exposure.”

When Jocie asked Dr. Jones how many children he had diagnosed since that February in 1973, even over the phone she could feel his embarrassment as he said, “I have no idea.” She doesn’t know if that’s true or not. But she felt that she was in the presence of a humble, good man who didn’t measure his success as a scientist in numbers of children diagnosed, and who, like Dave Smith, wanted to make a positive impact on the children and families whose lives he touched.

As they closed their discussion, Jocie felt compelled to ask one more question: “Dr. Jones I know a lot of people are saying that an FAS Behavioral Phenotype is not likely to be found. What do you think about that?”

With his customary gentleness he said, “Yes, that’s what a lot of people are telling me, but I think that is one of the most important issues. That’s not my field—it’s for people like Ann Streissguth and Claire Coles. But other syndromes like Down’s and Williams have common neurobehavioral phenotypes so it has always seemed logical to me that there is one for FAS.”

Jocie laughed and said, “Me too. I think the problem is that some people are heavily invested in not finding one.”

Dr. Jones had no comment. ♥

Preparing for a Diagnosis: Getting Your Ducks in Order

© FAS Family Resource Institute, 1992, rev. 2005, 2006

Gather and take the following documentation and pictures to your child's appointment with a medical doctor or at an FASD specialty clinic. [If you are a foster or adoptive parent, with no prenatal history on your child, you have a federally-guaranteed right to access the "non-identifying" medical and mental health birth family history of your child.]

History of Prenatal Alcohol Exposure

Sources to verify prenatal alcohol exposure:

- ◆ A birth parent (the ideal source)
- ◆ A paternal or maternal relative or friend
- ◆ A previous foster parent who knew the birth mom during pregnancy
- ◆ Your adoption caseworker (based on personal knowledge or written records)
- ◆ Written records from a hospital, doctor, treatment center, or adoption agency.

History of Your Child's Growth Pattern

- ◆ Was your child a "preemie" (born weeks before the due date)?
- ◆ Did your child have a "Failure to Thrive" diagnosis?
- ◆ Did your child have a low birth weight even though he/she was full term?
- ◆ Do you have access to your child's hospital birth records?
- ◆ Do you have medical records and/or school class pictures (smallest child in group) which document your child's growth deficiencies?

Physical Characteristics

1. Look for the most "typical" facial features of FAS:
 - ◆ narrow eye openings, causing eyes to appear wide-set
 - ◆ a short nose with flat bridge
 - ◆ long flat (or curved out) space between the bottom of the nose and upper lip (philtrum)
 - ◆ thin upper lip
 - ◆ flat mid-face
 - ◆ a small head in proportion to the body
2. Has your child had any of the following?
 - ◆ ear infections/hearing problems
 - ◆ seeing/eye difficulties
 - ◆ teeth/jaw malformations and/or braces
 - ◆ seizures
3. Collect a sequence of your child's photos (face shots, not smiling, if possible) between ages 5 and 10.

Central Nervous System Damage: Behavioral and Cognitive Characteristics

Does your child have the following traits?

- ◆ Difficulty concentrating or staying on task
- ◆ Problems connecting behavior to consequence
- ◆ Odd logic or reasoning
- ◆ Trouble thinking rules are only for other people
- ◆ Unpredictable and impulsive behavior
- ◆ Unable (as opposed to unwilling) to accept responsibility
- ◆ Lies with a clear conscience
- ◆ Manipulates others frequently
- ◆ Excessive vulnerability to peer pressure
- ◆ Multiple or pervasive developmental delays
- ◆ Volatile behavior (not necessarily violent or intentional)

In order to receive a diagnosis of FAS, a child/adult must have a history of growth deficiencies, the pattern of facial features, evidence of central nervous system damage and documentation of prenatal alcohol exposure. However, the large majority of affected individuals do not have the facial features. In these cases, many medical doctors who diagnose the spectrum of this disability, use the diagnostic term, Alcohol Related Neurodevelopmental Disorder (ARND). For this diagnosis, you will need to find a medical doctor, a scientific researcher or research team who is very knowledgeable and experienced in evaluating MRI studies designed to detect the specific organic brain damage involved in FAS/ARND. The professionals who are pioneering this type of research to establish diagnostic criteria are Dr. Fred Bookstein and his colleagues at the Fetal Alcohol and Drug Unit at the University of Washington (p. 3).

But the diagnosis of ARND is more typically made through comprehensive assessments, including a neuropsychological evaluation, done by a doctor or diagnostic team of doctors who are knowledgeable about the patterns of maladaptive behavior and cognitive deficits unique to prenatal alcohol exposure. If a diagnostic team or specialty clinic is not available in your area, this avenue for getting a diagnosis would probably require you to first educate your primary care doctor about FASD and then engage him or her to oversee the diagnostic process and refer you to identified specialists in the related areas: speech/language, child development, genetics, psychology (using the Vineland Adaptive Behavior Scale or the Achenbach Behavior Scale), etc., to rule out other causes of impairment. Once a diagnosis is made based on all the assessments, the diagnosis is very solid and will hopefully generate appropriate support services.



Wendy Kalberg...

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a psychologist who administers some of the neuropsychological tests with our children. Finally, we have a maternal interviewer who interviews the biological mothers who are available, so that we can get a clear idea of prenatal exposure.

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

A: I have worked on multidisciplinary evaluation teams my entire career, so I have been part of teams who diagnose children with all kinds of conditions, not just FASD diagnoses. In my career I have seen and diagnosed approximately 4,000 children. I have been a part of diagnosing approximately 400 children with FAS or a related diagnosis.

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

A: 40-60.

Q: Where do your referrals typically come from?

A: Our referrals come from a variety of sources: primary care physicians, social service agencies, biological families, foster families, school districts, etc.

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

A: Currently all of our referrals are being made because there is concern that the children may have a condition related to prenatal alcohol exposure.

Q: What diagnostic criteria do you use?

A: Our team uses the Revised IOM Criteria published by Hoyme, et al, in January 2005, Pediatrics.

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

A: We derive a diagnosis by considering three areas of information: (1) medical evaluation information (e.g., facial features, height, weight, head circumference, minor anomalies), (2) psycho-educational and neuropsychological data, and (3) maternal information on exposure. We believe it is imperative to have a medical doctor as part of the evaluation team because there are times when the children have other genetic anomalies that are not related to alcohol exposure. Some of these other genetic disorders can look very similar to FAS to someone who is not well

trained to look at the full spectrum of disabling conditions and etiologies.

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

A: The individual being evaluated may have a co-occurring condition that is in the mental health realm but this must be considered very carefully in the context of the child's life and family circumstances. Some children have mental health issues that are not necessarily related to alcohol exposure but more to the post-natal environmental influences. We collect extensive background information on each child to determine as best we can the child's experience over his life-span. If we are concerned about a mental health issue, we typically refer the child to local resource people to look more closely at potential mental health conditions. This process holds true for other disabilities as well. When we are concerned about a child with a different disability, we provide as much diagnostic information back to the family as we can and then we make certain that child is referred to the appropriate local programs and resources for follow-up care.

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

A: These other diagnoses are done according to the different protocols of the expertise of the team. When there are medical diagnoses, the doctors provide the criteria for the diagnosis. When there are other suspected psychological disorders, referral is made to the appropriate resources in the community. Our protocol (testing, questionnaires, etc.) is bound to a research project so the specific testing for other conditions is not a standard part of our diagnostic process. Therefore, if there

is a concern behaviorally or psychologically about a client, referrals to appropriate local resources are made. Included in the referral is the salient clinical information that we have collected that has provided reason for the concerns.

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

A: Yes, for the children who are diagnosed with FAS or another FASD diagnosis, we continue to follow the children year after year. We provide suggestions for school programming for affected children and work in concert with the family and the school teams to determine the best ways to develop appropriate programming for the affected child. Again, this is done on an individualized basis for each child.

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

A: My dream is that all children who have deleterious effects from prenatal alcohol exposure be given the best possible supports in order to develop into functional and happy adults. This process needs to begin with a diagnosis as early as possible. The diagnosis is then followed by a clear assessment of the individual child's abilities and challenges. This assessment should include standardized testing information as well as information from the family, the teacher, and from functional assessment data. Functional abilities of the child are only apparent in the context of the child's life in school, home, and the community. As far as I am concerned, the diagnostic label is only the beginning of the journey for these children and families. Helping the prenatally exposed child achieve a sense of membership, positive quality of life, and positive sense of self are the ultimate goals of this whole endeavor. ♥

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Susan D. Rich, MD, MHP

Department of Psychiatry and
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Washington, D.C.

Dr. Susan Rich was originally introduced to us in 2004 by Dr. Kieran O'Malley (a child/adolescent psychiatrist working with Dr. Ann Streissguth in the Fetal Alcohol and Drug Unit at the University of Washington). At that time, Dr. Rich was working on a proposal to the American Psychiatric Association to add the continuum of Fetal Alcohol Spectrum Disorders (including FAS, partial FAS, ARND and other neuropsychiatric disorders associated with prenatal alcohol exposure) to the Diagnostic and Statistical Manual (DSM). As most readers of FAS Times know, that has been a primary goal of FAS*FRI since early 1994 when Vicky, Ann and Jocie were appointed to Governor Lowry's FAS Advisory Panel.

While the decision has not been finalized to include these conditions in the next revision of the DSM, we have been very encouraged by the work of Dr. O'Malley, Dr. Rich and others. We firmly believe this is a critical step to help affected individuals, who do not have the facial features, to get an accurate diagnosis. In the meantime, being ever encouraged by their efforts toward this goal, we were recently delighted to receive a flyer from Dr. Rich announcing her latest venture, the establishment of an FASD Assessment Clinic in Washington, D.C.

The flyer explains that psychiatrists at the Children's National Medical Center (CNMC) are currently working with psychiatrists at the Kennedy Krieger Institute to develop consistent evaluation, diagnostic, referral and treatment guidelines for children and adolescents with FASD. It notes that there is currently no consistent way for psychiatrists to diagnose the spectrum of problems caused by prenatal alcohol exposure, although they are usually the clinicians who prescribe medications to treat the associated neuropsychiatric conditions caused by prenatal alcohol exposure. The flyer goes on to say, "Pediatric dysmorphologists diagnose FAS, but many pediatricians mistakenly believe there are no treatments available" so why should they diagnose it?

Patients evaluated in the FASD clinic at CNMC will receive a comprehensive psy-

chiatric diagnostic clinical exam, including a detailed history, to augment the parent and child questionnaires and other assessment forms sent with the intake packet. Patients may receive follow-up in the Department of Psychiatry and Behavioral Sciences and appropriate referral to other clinical and allied health professionals. Referrals may include, but are not limited to, developmental pediatrics, genetics, speech and language, neuropsychology, neurology, and/or nutrition. Children with a known or suspected history of prenatal alcohol exposure with psychiatric, neurodevelopment, behavioral and/or cognitive problems (ADHD, learning disabilities, and executive dysfunction) will be seen in this clinic. Other potential patients would be those with complex psychiatric medications management issues (e.g., not responding to standard treatments, etc.) with a known or suspected history of prenatal alcohol exposure.

When we inquired as to what brought her into the field of FAS from a career in pharmaceutical research, Dr. Rich's response was, "I was working in pharmaceutical research in clinical neurosciences in the early 1990s and met a post doctoral researcher at Cornell University Medical Center who had done work looking at the subtle changes in the neuromuscular junction of neonatal rat pups exposed in utero to very small (titrated) amounts of alcohol. He shared Michael Dorris's book, *The Broken Cord*, with me in April 1993. I read it on the plane back to North Carolina and couldn't put it down the following week until I finished reading it. The book changed my life.

"I began doing my own research and meeting with the department heads of North Carolina state health and human service agencies to find out what was going on in that state about the epidemic caused by our social drug of choice—alcohol. Soon after, I began going to Native American powwows and festivals across the state taking March of Dimes literature and a display board explaining how fetal development happens. This led me to begin writing grants, first with the March of Dimes, then with local agencies in Robeson County, NC. Needless to say, I left my career in pharmaceutical research in January 1994 in order to go to graduate school for a Master of Public Health degree. Later, after developing substance abuse prevention and

treatment programs in a rural area of NC for women in recovery and their children, I returned to school again—only this time, medical school—in order to become a national voice to speak about this issue. I have since chosen a career in adult and child/adolescent psychiatry, gaining additional expertise in FASD."

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

A. Mainly clinical practice—I have no research funding.

Q. What is your primary area of concern?

A. Diagnostic criteria.

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

A. I work in a teaching hospital and refer patients for multidisciplinary evaluations, then follow up with them to ensure the evaluations are completed and recommendations implemented. I do family work, individual work (particularly play therapy and supportive therapy) with affected children/adolescents and parent guidance.

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

A. Since beginning child training, I have assisted in the diagnostic evaluations of about 15-20 children/adolescents.

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

A. My practice is not solely working with children/adolescents with FASD. I see about 8 new patients a month for general psychiatric evaluations, and about half are referred because they have been prenatally exposed to alcohol or other substances.

Q. Where do your referrals come from?

A. The D.C. metropolitan area (Northern Virginia, Maryland, and D.C.).

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

A. 25-50%

Q. What percentage of your patients actually receives a diagnosis related to prenatal alcohol exposure?

A. 75-100%

Q. What diagnostic criteria do you use?

A. Referral to a geneticist for dysmorphic examination and testing; evaluation of documented (or suspected) history of prenatal exposure with low birth weight;

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The FASD Behavioral Phenotype: Personalized

Kenneth Dunning

*[Ken Dunning has been a counselor for over twenty-five years and a board member of FAS*FRI since 1993. We originally met him when he attended a training sponsored by FAS*FRI in early 1992. After coming to six or seven more FAS*FRI seminars, he remarked, "Every time I attend one of your conferences, I learn a bit more." Little did he realize that his half-brother would make it personal. Ken specializes in individual therapy for children and adults who have FASD and their family members. His clients have benefited greatly by Neurofeedback and other alternative therapies.]*

I was 16 when I met my half brother, Greg. I had heard about him frequently in our home as I grew up. Greg's mother and my Dad had split up when Greg was a young child. He was born in Dayton, Ohio where our father worked in construction and Greg's mom was a secretary. It was rumored that after they divorced, Greg's mother died of cirrhosis of the liver. True or not, I know from my own childhood that alcohol was often, if not always around and it was central to day-to-day life. I heard that at one time Greg had tried to come live with us when I was very young. For whatever reasons, things hadn't worked out and he returned to the west coast. But I was ready to be impressed by my "big brother" who was 29 years old when he came to visit us in Indiana in 1966.

Greg brought his wife and young daughter with him. They came by way of Chicago where he picked up a long, wide, late model, purple Pontiac with all the bells and whistles which he was taking back to Spokane (Washington) for a car dealer there. What an entry to impress a 16-year-old! He was dashing, charismatic and cavalier then. Physically he resembled an anorexic Clint Eastwood with something strange about his eyes, which maybe only served to provide a sense of mystery. He had stories of driving motorcycles and rally cars for a Datsun dealer. They all seemed to ultimately involve wrecking the vehicle in question and sometimes involved serious injury to himself. Greg didn't seem to be the most coordinated person in the world. But it was all fodder for the imagination of a teenager from a small town in southern Indiana!

We made a tentative plan that when I graduated from high school, I would go visit him. In May of 1968 I did so and spent that

summer getting glimpses of a world much larger than the one I had known previously.

During the late sixties and early seventies, Greg was an alcoholic's alcoholic. He could be the life of the party when he was lubricated. One liners could flow as fast and as potently as the alcohol. He was going through a fifth a day by his own estimate. He was taking a liquid "long walk off a short pier." Then a sort of salvation happened... Greg was taken in for a time by a single social worker who related to the counter culture and introduced him to pot. Alcohol became obsolete. Greg became mellow and didn't mind sitting in a room full of people talking about sophisticated social concepts, even if his contributions were usually limited to supporting more liberal thinking about sex, drugs and rock-and-roll. Those were the values Greg saw that needed to be championed—and Greg could be quite a champion of them. Thus the hippie/counter-culture movement and its legitimization of stepping outside the box conspired to camouflage Greg's disability.

In fact, the sixties and seventies, and even into the eighties, had to be heaven for people with FASD. Greg could get looser, faster than anyone I have ever met. And people striving to throw off undue psychological constraints in their lives could find a supportive friend in Greg. He could provide knee jerk reasons (and a few logical ones) for throwing off constraints with a speed and dedication that would put the broadband internet to shame. And he practiced what he preached...or maybe more accurately he preached what he practiced.

I'm sure Greg had a relatively high IQ. I wonder what he might have become had he not been hampered in fully assimilating and implementing what he could understand in his quicker moments. He was almost always charismatic and warm. Anyone not placing too many demands on the relationship could find an instant buddy.

Geography and circumstances also served to provide Greg with a way to earn a living and maintain some degree of respectability. Due to his being raised on a working farm while he was young, he developed a knowledge of farming and a work ethic. He really loved to work as long as he enjoyed the people he worked with. I think farm-

ing, wood cutting, or any physical labor in general provided a work environment where Greg was second to none. But he needed someone to do it with him. And there were farmers and woodcutters and others in need who were happy to have a good buddy who would work his fingers to the bone for housing, food, and occasionally a good used car, some money or pot. I don't want to make it sound like farmers and friends took advantage of Greg. He truly loved them and they really worked to see he was taken care of. He was truly blessed in this way. He had friends/resources he could nomadically rotate between, so they could get a respite from him and welcome him back the next time. They filled his life with meaning and I think he did some of the same for them. One very old and dear friend of Greg's shared with me that anytime he seemed to be getting too down and/or depressed, she knew the thing to do was to think up a work project (a roof, a fence, firewood, a garden, etc.), tell him about it, provide the resources needed and he perked up and was off and running. He took pride in his work. And through it all he smoked tobacco and, to a lesser extent, marijuana. His lungs took a beating but his liver and brain had gotten a reprieve from the alcohol which threatened his life so early on. And for Greg's life, he was all the more stable and mellow for it.

During all this time the mental health professional in me was looking for answers. In 1992 I learned about FAS at a presentation by Jocie DeVries and Sandy Randals. I was hooked. At that time I didn't equate what was going on in Greg's life with FAS yet, but I definitely recognized several clients. I stayed with the process of educating myself to the reality of the effects of prenatal exposure to alcohol and slowly it dawned on me that the real "hook" had been the explanation it provided for years of trying to understand my brother, Greg—the eyes, the always moderate-to-severe anorexic appearance, the learning deficits, the difficulties with traditional jobs, relationships, marriages, etc. Although if demands were low and Greg could come and go as he wished, he would keep friends indefinitely. He was the ultimate free spirit of the 60's. He did maintain a relationship with a beloved live-in companion for his last few years.

There was a constant search for new levels of stimulation, especially through his youth and middle years. **I truly believe that individuals with FASD seek stimulation as a form of self-therapy.** After all, stimulation is what leads our nervous systems and brains to develop fully and properly. **Doesn't it make sense that if something interferes with that process initially, our survival instinct will lead us to try over and over again to complete the process?**

Later in life, though, comfort and security increasingly began to matter. Greg eventually accumulated enough money to make a down payment on a piece of rocky land and a run-down house. As happened many times during his life, his friends came through—in no time the house was roofed, painted, and fixed up. Then, lo and behold, an acquaintance who was into beekeeping saw value in Greg's rocky but well located property and beekeeping became another source of friendship and income.

It's important to note here that Greg was never officially diagnosed with FASD. However, I cannot imagine that FASD was not present in light of his appearance, behavior and history. So in about 1998, I just began operating on the presumption that my own screening was accurate and Greg had FASD. I knew that Greg was not looking for a diagnosis and I could see no reason to push him to get one at that time. But understanding that Greg probably had FASD relieved my frustration and helped me find peace in our relationship. When I recognized him as being affected by prenatal exposure to alcohol, things began to make sense and nothing ever showed up to contradict my conclusion. I don't think that I shared my "diagnosis" with any of Greg's close friends until just before his death. They simply were caring, intelligent, flexible people who accepted Greg at face value, liked him over all, valued his friendship and responded to him in a mutually beneficial manner. The context and nature of their relationships allowed that and it seems to have worked. Sometimes when I see the difficulties that other affected individuals face in the world, I am astounded at how blessed Greg was in many ways.

Greg was greatly enabled socially by his early childhood education in farming and a work ethic. Having learned real-world skills early in life, he was able to contribute in a way that made him welcome in many places. With a few exceptions, a lot of Greg's friends

were loners—people who had varying degrees of success in the world at large, but who pretty much stayed to themselves. He was a social person who would gladly give attention to a topic if it meant he could enjoy company and be active. Without any conscious effort, he had the chameleon effect down pat and lived in the moment. While he might get judgmental if other people around him were, I think it rarely ever stuck. He could be anyone's friend—as long as no one was trying to diminish or inhibit his seeking of new stimulation. How many people knew a friendship they wouldn't have experienced if Greg hadn't been there? Greg was primarily interested in interaction but he also seemed to have a natural appreciation for life in general.

At one time I tried to get Greg hooked up with Neurofeedback treatment, but he thought it was a great joke. I arranged for another provider in the Spokane area to work with him for no fee. He did not seem to have any inclination to take advantage of it, which in my experience has been typical (especially for males with FASD) when faced with something that is therapeutic but not fun. I was not geographically close enough to provide ongoing support, structure and motivation. Although at various times during his life when one friend or another helped lead him, Greg was the recipient of massage therapy, chiropractic treatment, counseling, recreational therapy, some nutritional education, and "work therapy." I think it all helped to keep his life more stable and more healthful. As a mental health counselor, I kept my eyes and ears open through the years for every new discovery and development that promised to provide needed nutrition, stimulation and/or impetus toward health for his nervous system and brain.

I even sent a few valued books his way before I learned that for Greg the main value in books was in giving them away. An exception, that I believe Greg read cover to cover, was the illustrated book by Ram Dass entitled, "Be Here Now, Now Be Here." It is all about living in the moment and it spoke to Greg's heart.

Somewhere deep down inside, I just couldn't give up on the dream of the relationship I envisioned back in 1966. When, this autumn, I learned that Greg had been diagnosed with lung cancer and given two months to live, I found myself gradually and ever-increasingly feeling cheated. I

went into a grieving with roots extending back into childhood. I finally understood the depth of grief and pain some of the FAS*FRI parents had talked to me about.

Before Greg died, an old friend hurriedly threw a party for him. In essence it was his wake before the fact. Neither of his sons were present, but one daughter which he had not seen since around 1970 came from the east coast. Another daughter who lives closer was there; throughout his physical decline, she came to see him often and do everything she could to help him be more comfortable. This was despite his years of neglect of her and her needs. I think Greg's general lack of malice did a lot to make him an easy person to forgive for past slights. Greg had 5 grandchildren—three he had not met. He was introduced to one of these the day or so before the party. (He had previously met the two children of the daughter who lives closer.)

At the party, old friends and his newly introduced grandchild provided some truly excellent music. Greg sat tired, and I think more than a little in awe, taking it all in. As if in shifts, as it had been in his life, friends and loved ones sat with him to hold his hand and share a few words. After hanging around a little longer than we all expected he would, Greg quietly passed away mid-morning on Dec. 20th, 2005.

In thinking through all of this, I have come to recognize three absolutely invaluable truths. The first is that early, consistent education in real-world skills (both for living and employment) is vitally important. The second is that FASD does not go away. Trying to act as though it does only serves to deprive the affected individual of the support they need to have as full and rewarding a life as possible. Thirdly, I have learned how hard it is for so many parents, family members, loved ones and professionals to accept the second truth. But we must, for it profoundly determines how we react to and serve affected individuals. We all want to save the person who seems to perpetually be on the brink of putting it together...a brink which is in reality an insurmountable chasm.

Will there ever be a treatment? I think it's appropriate that we continue to hope and seek in that area. But in the meantime we need to recognize and accept FASD on its own terms, harsh as they may be. For only by doing so can we respond in a manner which truly serves affected individuals in a kind and compassionate way. ♥

Susan Rich...

Continued from page 8

prematurity; developmental delays and/or neurocognitive problems; and other related factors to distinguish FAS or partial FAS from ARND. In other words, the geneticist provides the dysmorphological data and chromosomal/genetic analysis to rule out other disorders and help clarify the extent of the facial dysmorphology. In absence of such features, or where there are fewer features than would warrant a diagnosis of full-blown FAS, then the possibility of partial FAS or ARND is considered. Drs. Ed Riley and Sarah Mattson at San Diego State University Center for Behavioral Teratology and Drs. Ann Streissguth and Keiran O'Malley at the University of Washington have provided insights for understanding the complexity of neurodevelopmental and cognitive deficits these children often face. Through my work with Dr. Paula Lockhart at the Kennedy Krieger Institute in Baltimore, MD, I have developed a comprehensive approach to understand the individual patient's unique strengths and limitations to help guide further diagnostic evaluations and referrals (e.g., neuropsychology, speech/language, physical/occupational therapy).

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

A. Not at all. I believe the neuropsychiatric, neurobehavioral, social functioning, cognitive abilities, and developmental issues are more important – those factors (and not what they look like) will determine their functional limitations and strengths.

Q. Do you diagnose other conditions (besides FAS) caused by prenatal alcohol exposure?

A. Yes.

Q. If yes, what do you call these diagnoses/conditions?

A. The mental health diagnosis (e.g., learning disabilities, ADHD, mental retardation, motor skills disorders, etc.) is made secondary to the general medical condition (prenatal alcohol exposure or PAE).

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

A. DSM IV-TR. If the patient meets criteria for a mood disorder, but not the strict criteria for Bipolar Disorder, I qualify the diagnosis as being secondary to a general medical condition, prenatal alcohol exposure. In cases of ADHD, I strongly feel it is important for clinicians to be aware that ADHD associated

with PAE should be carefully considered (in terms of treatment and medication management) due to the medical risks that many of the children have.

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

A. Yes and No. Many of the patients referred to see me will continue to see their primary psychiatrist and therapist as they are coming to me for an evaluation only. I do follow a number of patients for several visits after the initial diagnostic sessions in order to ensure proper follow-up on referrals I have made. Additionally, I have patients in my clinic who I see for medication management, play therapy, family therapy, and related treatment.

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

A. Yes, in most cases.

Q. What is your dream for the future of diagnosing?

A. FAS: That psychiatrists are able to diagnose the disorder (since we are the ones involved most often in long term treatment). ARBD: There are very few cases of ARBD in which there are no associated neurodevelopmental or neuropsychiatric sequelae (i.e., conditions arising from the birth defect). I have never seen any. To me, if these children exist (in rare cases), their problems are mostly medical in nature.

ARND: That better diagnostic descriptions are established since the DSM-IV TR does not fit well for this spectrum of problems.

FASD: That a diagnostic framework similar to the continuum for Autistic Spectrum Disorders or Alcohol Use Disorders be established to help guide future research, clinical practice, patient care, and ultimately prevention. ♥

H. Eugene Hoyme, MD

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Readers of FAS Times may remember Dr. Hoyme as the primary author of the 2005 article, *A Practical Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine (IOM) Criteria*. (See review of

article, FAS Times, Spring 2005.) The children, who participated in the study on which the article is based, were identified through active case-ascertainment methods, in six American communities in the U.S. and one community in the Western Cape Province of South Africa. The children and their families underwent standardized multidisciplinary evaluations, including a dysmorphology exam, developmental and neuropsychological testing, and a structured maternal interview, which gathered data about prenatal drinking practices and other demographic and family information. Data for these subjects were analyzed and revisions and clarifications of the existing IOM diagnostic categories (fetal alcohol syndrome - FAS; partial fetal alcohol syndrome - PFAS; alcohol related neurodevelopmental disorder - ARND; and alcohol related birth defects - ARBD) were formulated on the basis of the results. The revised IOM diagnostic method defined accurately and completely the spectrum of disabilities in a large cohort of children who were prenatally exposed to alcohol. This critical research was funded in part by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the National Institutes of Health Office on Minority Health and Health Disparities and the Mosbacher Family Distinguished Packard Fellowship of the Lucile Packard Children's Hospital at Stanford. The positive prognosis for affected individuals and their families is immeasurable because of the power of this research. Dr. Hoyme writes, "On the basis of our extensive experience with alcohol-exposed children and adults in the U. S. and South Africa, we propose a modification of the 1996 IOM diagnostic criteria for FASD, making them more specific and clinically applicable in general pediatric practice. Our aim is to improve both the reliability and validity of diagnoses within the FASD continuum."

Curious about the origin of his passion toward helping isolated and suffering families, we asked Dr. Hoyme what it was that originally brought him into the field of FAS. He answered, "I am a pediatrician and a dysmorphologist. I trained in dysmorphology with Dr. Kenneth Lyons Jones at UC San Diego. Along with Dr. David Smith, Dr. Jones was one of the co-authors of the original article describing FAS in the English-speaking medical literature. It was during my training with Dr. Jones in the late 1970's that I developed my passion for this

Eugene Hoyme...

Continued

field. I have subsequently served as a faculty member at the University of Vermont, the University of Arizona, and (for the past 9 years) at Stanford University. During my tenure in Arizona, my colleagues and I evaluated over 500 children prenatally exposed to alcohol, and these children, adults and families convinced me that there was a need for a more uniform and comprehensive approach to the diagnosis of children with FASD.

Q: How long have you been in the field?

A: I have been interested in FAS since 1979.

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

A: Both.

Q: What is your primary area of concern?

A: Diagnostic criteria, prevention and intervention.

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

A: In my research, I work in depth with a specific multidisciplinary team (from the University of New Mexico) that includes professionals from a number of disciplines: dysmorphology, psychology, neuropsychology, special education and maternal interviewing. In my clinical practice at Stanford, I gather information from health professionals in education, psychology and neuropsychology for any child I evaluate for potential FASD prior to my dysmorphology examination. Prior to my examination, I also review all medical records, reports and testing in addition to the biological family history, if available. After gathering these data, I assign either an FASD diagnosis or another (often genetic) diagnosis for a particular child's disability.

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

A: 800 FASD patients.

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

A: I evaluate approximately 40-50 dysmorphology patients per month. Of those, approximately 5-10 are referred to rule out FASD.

Q: Where do your referrals come from?

A: My referrals come from the foster care system, pediatricians, family physicians, and self-referrals from families themselves.

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

A: As above, about 25% of my practice is related to FASD referrals.

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

A: Approximately 50% of those referred to rule out FASD.

Q: What diagnostic criteria do you use?

A: I use the Revised IOM Criteria as published recently in *Pediatrics* (Hoyme et al: *Pediatrics*. 2005 Jan;115(1):39-47)

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

A: The Revised IOM Criteria use the presence or absence of prenatal alcohol exposure, growth parameters, a small head circumference or other structural brain abnormality, characteristic objective facial features, and the learning and behavioral profile to assign diagnoses within the FASD continuum. (See reference above.)

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 do you call these diagnoses/conditions?

A: The diagnostic categories are: FAS, partial FAS, alcohol related birth defects (ARBD) and alcohol related neurodevelopmental disorder (ARND).

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

A: Revised IOM Criteria, as above.

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

A: Sometimes. I always offer follow-up; however, because of distance, health insurance or the comfort of the referring physician with caring for children with FASD, the family may decide all that is required is a one-time diagnostic visit. I always make my services available again to any patient if new issues arise...even if I don't follow him or her regularly.

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

A: We always recommend appropriate medical/psychological/educational interventions for each patient. Follow-up is

variable, as above.

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

A: Yes, as is necessary.

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

A: Annual follow-up visits with a multidisciplinary team and more frequent visits as needed.

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

A: Widespread acceptance and use of the Revised IOM Criteria so that all affected children will have the availability of diagnosis and treatment.

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

A: Widespread acceptance and use of the Revised IOM Criteria so that all affected children will have the availability of diagnosis and treatment

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

A: This diagnosis remains problematic because, although psychologists and neuropsychologists have moved closer to suggesting a unique phenotype for this diagnosis, we are not yet there. My dream is that such a specific profile will be developed, allowing for accurate diagnosis and intervention for children affected with ARND.

When asked about his current projects, Dr. Hoyme stated he is involved in the following areas of study.

◆ Determining diagnostic parameters for FASD in infancy—a new project that will be carried out in South Africa.

◆ Epidemiology, diagnosis, treatment and intervention for FASD in the Native American population of Northern Plains (in collaboration with Dr. May at UNM).

◆ Epidemiology, diagnosis, treatment and intervention for FASD in South Africa (also in collaboration with Dr. May at UNM).

◆ Consultation to the PASS project, evaluation of the role of prenatal alcohol exposure in SIDS and stillbirth in the Northern Plains and South Africa (in collaboration with Harvard University and the University of South Dakota).

Any patients wishing to request an appointment, may contact Dr. Hoyme at (650) 723-6858. ♥

Phil May...

Continued from page 3

and research protocol for FAS. A year later, a follow-up study, *Epidemiology of FAS Among American Indians of the Southwest*, was published with Jon Aase, Jonathan Samet, and Karen Hymbaugh in the scientific journal, *Social Biology*. This study focused on specific populations of Navajo, Pueblo and Plains native tribes where a total of 115 alcohol-affected children were identified.

The third major project by Dr. May (with Karen Hymbaugh) was published in 1989 in the *Journal of Studies on Alcohol*. The article reported on research to develop: *A Macro-level Fetal Alcohol Syndrome Prevention Program for American Indians and Alaska Natives*. **The goal of this program was to provide native communities throughout the U.S. with the knowledge, skills, and strategies to initiate effective and culturally-appropriate prevention measures**, which would be unique to the needs and norms of each community. The key purpose of the project was to provide training to a cadre of trainers/advocates in local Indian and Alaska Native communities served by the Indian Health Service. With this distinguished track record, Dr. May continues to do research in the American Indian and Alaska Native cultures and periodically publishes data gathered from this research base.

Over the years, Dr. May's collaborative work has steadily grown and now includes a large number of scientists gathering data on ethnic groups across the globe. In 2001, he along with several colleagues (Colleen M. Adnams, Piyadasa W. Kodituwakku, Andrea Hay, Chris D. Molteno, and Denis Viljoen) published *Patterns of Cognitive Motor Development in Children with Fetal Alcohol Syndrome from a Community in South Africa* in the scientific journal, *Alcoholism: Clinical and Experimental Research*. This article is significant in several ways, one of which is the inclusion of a comprehensive outline of previous research that has documented the cognitive dysfunction in children with FAS as follows.

- The average IQ of these children is in the borderline range: 70-79 (Mattson, et al, 1997; Streissguth et al, 1990)
- On tests of academic achievement,

children prenatally exposed to alcohol tend to earn lower scores on arithmetic tests than on other tests. (Streissguth, et al, 1994)

- There is increasing evidence that alcohol-exposed children are deficient in different components of attention and executive functioning (Coles, et al, 1997; Kodituwakku, et al, 1995)
- Various other researchers have obtained evidence of impairments in:
 1. information processing (Jacobson - '98)
 2. number processing (Kopera-Fry et al, '98)
 3. visual memory (Uecker and Nadel, '96)
 4. verbal learning, memory (Mattson et al, '96)
 5. language (Abkarian, '92)
 6. motor function (Roebuck et al, '98)
 7. Behavioral and emotional difficulties (Steinhausen and Spalac, '98)

This article goes on to describe in detail the purpose and focus of the authors' work in South Africa. In other related research articles from the Western Cape of South Africa, a research team of which Dr. May is the Principal Investigator, found the highest prevalence of FAS ever reported around the globe and 100 "gold standard" cases.

Also in 2001, the article, *The Effects of Prenatal Alcohol Exposure on Executive Functioning* authored by Piyadasa W. Kodituwakku, Wendy Kalberg and Philip May was published in *Alcohol Research and Health*. The essence of the data was that people who have been exposed to alcohol prenatally may exhibit impairments in the performance of relatively complex and novel tasks. **These tasks include tests designed to measure executive functioning (EF) or the ability to plan and guide behavior to achieve goals in an efficient manner.**

For a more comprehensive look at Dr. May's amazing quality and quantity of research, please see the associated articles on Dr. Hoyme (p. 12), Dr. Robinson (p. 5) and Ms. Kalberg (p. 5). ♥

Luther Robinson...

Continued from page 5

- ♦ intact—relatively low mobility in the community;
- ♦ possibility to do comprehensive maternal interviews on affected children. Maternal drinking variables indicated that the mothers of all children with FAS were likely to be drinking more at the time of the interview. Furthermore, almost 90%

of all alcohol consumed at the time of the interview by both groups was on weekend days, i.e., the children all lived in a similar cultural environment—92.3% of the case mothers reported drinking during pregnancy, and 88.7% - 92.5% reported drinking about the same amount throughout the trimesters.

- ♦ possibility to document the drinking habits of the fathers of the children. Ninety-six percent of the case fathers currently drink compared with 73% of the controls. Drinking fathers of children with FAS consumed 84.6 drinks per months, compared with 47.5 for drinking controls. Fathers of children with FAS were more likely to be reported as having a drinking problem than controls and to be farm laborers. It was clear that residing on some of the fruit and wine-producing farms in the region is a grave risk factor because severe episodic drinking is perpetuated by norms within a context of poverty, despair and hopelessness.

Fruit, grape and wine production dominate the region. Wine production over the past 300 years has influenced the modal drinking patterns. Wine was historically distributed daily to workers as partial payment for labor, under what was called the 'Dop' system. Dop was outlawed by multiple statutes and there is general public sentiment against its practices, but residual patterns of regular, heavy episodic alcohol consumption by some are a legacy.

The children in this study were each examined by four two-person teams (one dysmorphologist and a physician being trained in diagnosis). Every team worked independently but simultaneously, using standardized Institutes Of Medicine (IOM) assessment criteria. It is important to note that the evaluations did not stop at the point of a dysmorphology examination but continued with an interdisciplinary, multiple-domain, control-group design that we believe is complete, accurate and reliable knowledge of the prevalence and characteristic of FAS. Final diagnoses were made only after case conferences were held for each child. Results from dysmorphology examinations, developmental testing and maternal interviews (each domain completed by independent investigators) were presented at the structured case conference. Furthermore, as of the completion of this second wave of research in this community, these studies have identified 100 "gold standard" cases for further research and for

clinical services. That's the good news.

The magnitude of the problem is substantial. Most of the children were born in 1993, one year before the end of apartheid. Past apartheid policy (enforced segregation by ethnicity), resulted in an overrepresentation of individuals in lower SES, as is clearly reflected by the concentration of cases in the poorer, rural areas. But the sad news is that the rate of FAS among children in this study is 60% higher than reported in our similar and previous South African study. We can speculate on the possible causes of this increase, but whatever the cause, the rate of increase in an already alarming rate (the first study found 40.5-46.4 affected children per 1,000 and the second, 65.74 affected children per 1,000) is cause for grave concern.

Those of us who have worked on the South Africa project feel that a new era of understanding has opened up on the consequences of prenatal alcohol exposure. The data show the affects on the children already born, revealing many of the vulnerabilities of their family situations and the critical changes that must be made if societies around the globe want to prevent these birth defects in future populations. Comprehensive studies similar to the South Africa research are currently under way in other parts of South Africa, in Washington D.C. and in Italy. ♥

Save the Dates!

DASA Treatment Institute

July 6-8, 2006

Seattle Pacific University

Pam Sacks-Lawlar (360) 725-3812

DASA Prevention Summit

October 18-20

Kennewick, WA

Steve Brown (253) 476-7015

Co-Occurring Disorders Conference

Sept. 18-19, 2006,

Yakima, WA

Ruth Leonard (360) 725-3742

LIFE in the FAS LANE

Pam Medgard

I had worked so hard keeping Alex from eating or drinking all morning because, according to the dentist's instructions, Alex wasn't supposed to have anything to eat or drink until after his appointment. Once in the car, Alex found an unopened bottle of water. He was determined he was going to have a drink. I thought maybe I could roll down my window and try to grab it out of his hand by reaching in the back seat, but I figured he would probably be quicker than I was or I would end up driving off the road. After some fast talking I was able to get him to set it down. (Now I know how the police feel when they try to talk a gun away from some deranged person.) I finally convinced him that I would not let him die of thirst.

I changed the subject to get his mind off food and water-when suddenly, Alex's primary aide Amy announced, "I am starving. I haven't had anything to eat since 11 last night. I have a migraine and I am feeling sick. I think it's low blood sugar from not eating. I really need something to eat, now!"

In spite of all the complaints, I artfully dodged her demand and finally got Alex into the dentist's office. I leaned over and whispered to Amy, "See if Alex will play foosball with you to work off some of his anxiety." Amy just stared at me. I waited a few seconds and could tell it hadn't sunk in. I tried again. "Amy, Alex is very anxious. See if he will play the play station or foosball with you, OK?" She said, "No. I am starving, I haven't eaten since 11 last night." I finally said, "Hey Alex, let's play foosball." No dice. Instead we all three sat gloomily for 40 minutes...just waiting. When Alex finally went in to see the doctor, I could have kissed the receptionist. While he was with the dentist, I walked next door to get Amy some food. When I suggested protein, she assured me that large fries and a large milkshake would be best for her low blood sugar.

I met Anthony (Alex's aide from Service Alternatives who works with Alex on the second shift) at the dentist. He went with Amy and Alex to buy the play station game. He called me to say it was a little

more expensive than we thought-\$65. Plus both Amy and Alex were so hungry they had to stop at KFC (and that little diversion cost \$22 for both their lunches). Add the \$7 it cost to get Amy's blood sugar up and it cost me \$94 for a dentist appointment that doesn't include the actual doctor's fee.

Anthony brought both Alex and Amy home. I decided to go to lunch in Wenatchee with my other son, Travis. As I got back home into Chelan, I got a call from a very irate Alex who was at home by that time. He had locked himself in the bathroom with the phone and pliers. He told me the tooth hurt bad and he was going to pull it out. I convinced him to wait for me because it would be easier for me to do it.

My husband, Harley, and Anthony were locked out. Alex allowed me in because I said I would help him. Harley told me he had given Alex some Tylenol so I knew I would have to stall until it took effect. I took 5 minutes trying to find the right tooth. I knew that 5 minutes was all he would tolerate when he starting to call me all the stupid names. So I looked at the pliers and said, "My goodness these are filthy" and I began washing them with hot water and soap. OK, that was good for 5 more minutes. I placed the pliers in his mouth, checked again to make sure it was the right tooth and said, "Wait! I am calling Tari to make sure I pull this out the right way." When she answered the phone I explained that we were pulling the tooth that was just filled because it hurt Alex so badly. He was nodding his head in agreement. She is so good, she caught on right away and yelled in the phone (loudly enough for Alex to hear), "No don't do that! He will bleed to death!" His eyes got really big. I said, "Oh Alex, I would have killed you!"

Either the pain pills took effect right that minute or the thought of bleeding to death eased the pain. Either way, he was able to walk to his chair and continue playing his new game-his new expensive game. That's the good news. The bad news is that Alex still has one more cavity... ♥



Jocie,

You may remember me—the gal with the white hair—we met about 15 years ago. I was able to get my son diagnosed about a year after we met. Thought you might want to use his story sometime in FAS Times. The diagnosis helped him to get into many services. I have been a faithful reader of FAS Times for many years. You all have done a superb job of spreading the word about FAS/FAE.

Sincerely,
Cammy M.

The following are notes we have received in response to our last (Winter 05/06) issue of FAS Times, FASD: Diagnosing the Spectrum - Part 1.

Wow, this is fantastic. You guys do the best newsletter! I want to show this to every person on our Task Force.

Teresa Kellerman
FAS Community Resource Center

Hi Ladies,

I just wanted to drop you a quick note to say how much I appreciated this edition of the FAS Times. It is wonderful to learn more about the health care providers around the country that are working in the field. I especially enjoyed the story about what is happening in Mossyrock as I'm in the midst of working with a group here in Anchorage that is trying to get a second diagnostic team in place that will be able to evaluate non-native children, youth and adults.

Thanks to all of you for continuing to lead the way—and report back to us from the edge!

Best wishes for a peace-filled spring.

Cheri Scott
FASD Parent Support Project
Stone Soup Group

Dear Mrs. DeVries and Staff:

As I sit with my “fit-throwing” nine-year-old, this last issue of FAS Times is open before me and I am so grateful!

I remember the first gathering of FAS in Tacoma (that I attended four years ago). At the time we lived in Washington and it was the first time I had been alone with my thoughts since the boys came home. I remember sitting and listening and thinking I might just start weeping right in the middle of the presentation. My babies were pre-schoolers then and you understood the world I live in each day.

I was overwhelmed, relieved and encouraged. You told me about books to read, people who might help, resources. I saw in your eyes resolve, peace and wisdom. I saw the same look in the eyes of the other mothers. It is not a wisdom most moms get to achieve. It is not a path I would have chosen. But I am honored to be among the ranks of parents who, by God's grace, help the challenging ones. And thank you—you have made a profound difference in the life of our family.

Joyce C.

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