

# iceberg

march 2002

volume 12 number 1

an educational  
newsletter for  
people concerned  
about fetal alcohol  
syndrome (FAS)  
and fetal alcohol  
effects (FAE)

■ ■ ■

because the  
problems we  
readily see  
are only the tip  
of the iceberg



## Updates from FAS communities worldwide

*Edited by Katy Jo Fox*

**M**ore than 30 years have passed since the French doctor, Paul Lemoine, first published his research regarding the health of children born to alcoholic mothers. Shortly thereafter, Kenneth Jones, M.D., and his team in Seattle, Washington, first started looking for the markers of the condition now known as Fetal Alcohol Syndrome and the teratogens that caused them. Soon researchers from Germany, Sweden, Finland, and Russia were reporting their findings.

What has happened because of this research? Who is making sure that this life-altering information is available to laypeople? For answers, I contacted people from all over the world whom I have met in my own journey towards FAS awareness. Let their accomplishments give you a renewed sense of empowerment and motivation. Change does happen, and individuals can have an effect on the direction change takes.

### **Australia**

There is a general lack of awareness and recognition of Fetal Alcohol Spectrum Disorders (FASD) in Australia. Diagnosis, intervention, and management for affected individuals are virtually nonexistent. Public policy in Australia reflects the view that the prevalence of Fetal Alcohol Syndrome in this country is small. Recently released Public Health guidelines for responsible consumption of

alcohol suggest that it is only episodic consumption of large quantities of alcohol during pregnancy that is of concern.

A small group of volunteers formed Australia's first support group—National Organization for Fetal Alcohol Syndrome and Related Disorders (NOFASARD). We provide e-mail and telephone support to people from all over Australia.

Consistent lobbying by NOFASARD has helped. The South Australian Child and Youth Health and Disability Information Resource Centre have updated their web sites to include information about FAS. The Drug & Alcohol Services Council initiated a Fetal Alcohol Syndrome Task Force, which has handed its recommendations for prevention to the Minister for Human Services, and is now awaiting outcome.

NOFASARD had funding approved to publish and distribute informational brochures to Women's Health Centres in South Australia. A Queensland member secured local Rotary Club funding to do the same in her state.

— Sue Miers, [miers@cobweb.com.au](mailto:miers@cobweb.com.au);  
<http://users.chariot.net.au/~miers/>

**The Ontario  
provincial  
government  
earmarked  
\$1.4 million this  
year for FAS/E.**

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# iceberg

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## FAS worldwide

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### Canada

Minister Anne McLellan, former Minister of Justice, recently moved to the Health ministry. She follows a predecessor who announced \$25 million over the next two years from Health Canada for FASD prevention and support to aboriginal reserves, where as many as one in ten children may have FASD.

Health Canada has created or funded other numerous projects and programs at both federal and grass-roots levels including Best Practices manuals, and awareness materials. Current Ministry projects include: a national survey to determine the state of knowledge and need for training of health care professionals; developing national guidelines for diagnosis; and holding a national awareness campaign.

British Columbia has joined the alliance known as the "Prairie Northern Pacific FAS Partnership." Four provinces and three territories will now be working together for prevention and awareness.

In Eastern Canada the Ontario provincial government earmarked \$1.4 million this year and \$2.3 million for the next two years for FAS/E awareness and frontline training in Aboriginal communities. In addition, Ontario's Aboriginal Management Committee, with financial support from Health Canada, will be sending five medical teams for "training in assessment and intervention strategies."

For the third time, members of the federal parliament are attempting to pass legislation that will force beer, liquor and wine manufacturers to put warning labels on all alcoholic beverage containers. A final vote is expected before the summer recess at the end of June, and we are confident that this time it will pass.

— *Bonnie Buxton, ogrady@axxent.ca;*  
*www.fasworld.ca/*

### England

Our first encounter with FAS was when we learned that our 18-month-old foster child had FAS. We lived in South Africa at the time and worked to create FAS awareness in Cape Town (FASSA), where there was reported to be 4,000 +/- FAS births per year in the Western Cape. Matthew was officially diagnosed at age four, and we were advised to give him back to Social Services. The doctor did not know us. We adopted Matthew.

After returning to the U.K. in 1999, we began all over again. Teresa Kellerman, with whom we first made contact via FASlink, provided help and advice. Besides being an advocate, she donated space for our website, which has given us much credibility. Margaret Murch who heads the FASTrust in Liverpool also gives us support. Peter and I concentrate on FAS awareness, non-judgmental support groups and a resource centre.

For FASUK's part in FAS Day 2001, university students agreed to research FAS and put together a poster for us. Peter and I delivered the winning poster to every maternity clinic in two communities, as well as Billinge, our local unit. We received our first donation from the TAWD Vale Lions Skelmersdale. I was also interviewed and filmed by the Discovery channel.

In December, we were granted funds by the Skemersdale Champions to be used for creating posters and leaflets. This is the best news yet, because it represents acceptance. In the same week, the Children's Fund in Manchester requested that we apply for funding.

The aims for 2002 are to secure a charity number. Then we can secure further funding. In the last two years, we have been giving our all and funding it out of our own pocket. FAS awareness is growing slowly. Peter and I know that it can only get better.

— *Gloria & Peter Armistead,*  
*pa0013478@blueyonder.co.uk,*  
*www.fasstar.com/UK/*

## Germany

FASworld Germany began in February 1999 as a result of planning the first FAS Day. What began as a one-woman show has managed to hold three FAS Days with information stands; to provide a seminar with Prof. L'ser; to get a website up and running; and to release and distribute a FAS-information CD ROM in German, English, French and Spanish. Funds were donated from a children's charity and Germany's Social Ministry to have pens, balloons, and t-shirts with a FAS logo made. The government-funded Central Office on Addiction has also supported us by printing 1000 brochures.

We now have an online FAS support group. In August 2001 we sponsored a "FAS Cup" at a county-wide riding tournament, and had 6x3' banner made through the kind donation of a famous German Artist.

The International Order of Good Templars have chosen FAS/E as its main theme for 2002, and I've already printed posters for their FAS Day activities. Unfortunately, Prof. L'ser retired, but we are in close contact with Professor Spohr in Berlin and the Addiction Spokesman for the Christian Socialist Union in the German Parliament, and are hoping to hold a large event in Berlin on FAS Day 2002. We have submitted a private petition to the European Parliament asking for warning labels on all alcoholic beverages. In the last three years we've had two television appearances, with another on the most popular German current affairs program due out in the next couple of weeks. There have been numerous newspaper/

magazine interviews, and I was in the top three for a "Do Gooder's" prize for FASworld Germany. At the moment we have no funding, which means all members are donating their own money for printing, etc.

— *Ann Gibson, gibsonanni@aol.com;*  
*German version: <http://fusae.freesevers.com/web3.html>;*  
*English version: <http://fasalkoholembryopathie.freesevers.com/>*

## The Netherlands

In the Netherlands, there is a foundation of FAS awareness among professionals—physicians, teachers and social workers. The professionals, however, often lack the knowledge and experience to assist and advise parents who are raising children with FAS. Currently, we are getting together a core of experienced and motivated parents and professionals who are already serving as resource persons in their local areas. In the next few months, we hope to organize an official support group with a website, both to help each other as parents, and to provide public education with regard to FAS diagnosis and prevention.

— *Diane Black, dblack@ision.nl;*  
*Martha Rooda, mrooda@freeler.nl*

## New Zealand

Although the Alcohol Liquor Advisory Council (ALAC) recently changed their recommendations about drinking during pregnancy to "zero consumption," they do not believe in warning labels. One of our local Members of Parliament, Dianne Yates, has put forward three times a submission to the Government Select Committee concerning liquor labeling and all three times it has been rejected.

Fetal Alcohol New Zealand (FANZ) put in a submission once again. We are still awaiting the outcome.

New Zealand has numerous organizations that provide information on FAS/E. FANZ, funded by ALAC, is made up of people who specialize in various areas of FAS awareness and intervention. Regional groups provide their own funding, parent support groups, and networking. A government-funded trust in New Plymouth targets Maori (Indigenous people), but has a multi-cultural client-base as well. I founded Fetal Alcohol Support Trust (FAST), an organization in Hamilton.

Coinciding with FAS Day, on September 17, a TV documentary titled "Drinking for Two" was shown throughout New Zealand. The response from that one show has been phenomenal! We are still getting phone calls.

The big problem now is that we don't have the professionals to diagnose our adults and, like the rest of the world, they are filling our prisons and mental health services. Doctors in New Zealand are unable to give a diagnosis unless they see the full FAS face. We refer many children to pediatricians who then diagnose them as ADHD, Asbergers, Fragile X. For teens and older, it's schizophrenia, bi-polar, or anxiety disorder, and they occasionally throw in bad or dysfunctional parenting. This needs to change.

— *Shirley Winikerei, fast@xtra.co.nz*

**A TV documentary titled "Drinking for Two" was shown throughout New Zealand.**

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## FAS worldwide

CONTINUED FROM PAGE 3

### Poland

For the first International FAS Day in Poland, we invited a guest speaker from the U.S.—Toni Hager (Kids Can Learn). It was organized in the cinema hall of a little town called Ledziny, and broadcast by the main Polish TV channel!

This year we are planning to organize FAS Day events in several towns in Poland. We are looking for volunteers and guests speakers

who are ready to support us in those events.

I organized and led the first training for “FAS teachers,” as I call them, so they can be prepared to train others. This is a group of 30 people from all over Poland who are both interested in

FAS issues and ready to bring FAS awareness into their fields—neurologists, psychologists, teachers, officials, foster parents, orphanages, adoption centers workers, and pedagogues (specialists dealing with the physical and social development of a child).

I also received a scholarship from an organization called Ashoka ([www.ashoka.org](http://www.ashoka.org)) to develop my FAS project in Poland for one year!

—Gosia Klecki, [elkana@pro.onet.pl](mailto:elkana@pro.onet.pl)

**This year we are planning to organize FAS Day events in several towns in Poland.**

### Scotland

It has been a wonderful year over here in Scotland. We have been up and running for almost two years now and have had many inquiries from parents, caretakers, and from the professionals that didn't know we existed! We are in the beginning stages of talks with the Government. The drastic changes, which took place this past year in our Parliament, have made this more difficult. We applied to become a registered charity and now await their decision.

FAS Scotland has had enormous help from Margaret Murch who runs the FAS Trust in Liverpool, England. Together we are raising the awareness of FAS. We have had a lot of success with our new phone line. I would like to thank Teresa Kellerman for her enormous help with our web site; she has been fantastic.

—Jane Murphy,  
[jane@hawick06.fsnet.co.uk](mailto:jane@hawick06.fsnet.co.uk),  
[www.fas\\_scotland.homestead.com/](http://www.fas_scotland.homestead.com/)

### South Africa

In South Africa things are moving slowly, but positively, in the right direction. There are various studies being done in schools in different parts of the country, with alarmingly high incidences of FAS being found in the winelands.

On a personal note, Peter and I are being asked to speak on radio programs and we also have written some newspaper articles. Because of our efforts to get the bells ringing on International FAS Day, the Medical calendar has included September 9 as FAS Day. This is a fantastic move forward, as more people will now run awareness campaigns on this date.

—Vivien Lourens,  
[plourens@mweb.co.za](mailto:plourens@mweb.co.za)

### Sweden

In the 1980s, the danger of drinking during pregnancy was discussed in Swedish media and the number of children with alcohol-related birth defects went down. Today, young Scandinavian girls drink more than ever and it has become customary to go out for a drink after work. The knowledge about the danger of drinking during pregnancy seems to have been forgotten.

In 1999 I started up the first Swedish support group, FAS-föräning (FAS association), together with some other families with FAS/FAE children. Our mission is two-fold: connecting people, both parents and professionals, and sharing information about FAS/FAE. The need for information is huge! For that purpose we started a mailing list, and have made up brochures, handouts and a poster. I have published my book, *Eric: A Child Among Us*, and I'm glad to say that I have sold more than I expected. Yesterday I got an invitation to talk at a conference in October. There will be about 300 people attending and I'm already nervous! But it is a fantastic opportunity so I will turn off my nerves, if it's possible.

For 2002 we plan to start weekend education seminars for parents, teachers, social workers, and others. We are able to do this thanks to money from the government, insurance companies and others.

Norway has a support group that has been in existence since 1996, Aline-föräning, with whom we cooperate and share information. We look forward to making a combined Scandinavian network in the future.

—Katarina Wittgard, [fas@telia.com](mailto:fas@telia.com),  
[www.fasforeningen.nu/](http://www.fasforeningen.nu/)

Katy Jo Fox is an office assistant/web mistress for the Fetal Alcohol and Drug Unit <http://depts.washington.edu/fadul>. She graduated with a degree in European Studies and hopes to eventually be an advocate for FASD in Europe. She can be contacted at [katyjofox@hotmail.com](mailto:katyjofox@hotmail.com).



**The International Center on Alcohol Policies web site is a good source for information on alcohol policy worldwide.**

**For information regarding specific government guidelines and recommendations on alcohol use during pregnancy, go to:**

**[www.icap.org/publications/report6.html](http://www.icap.org/publications/report6.html)**

# A letter edged in black

by Dr. Ann Streissguth

A few days ago at the Fetal Alcohol and Drug Unit, we received a letter edged in black. I knew immediately what it meant and felt a wave of anxiety sweep over me. I remembered from my childhood the sadness that prevailed when my parents, both immigrants, received a letter edged in black and mourned the loss of another relative I'd never met, from countries I had never seen and could only imagine.

This letter announced the untimely death of Prof. Dr. (med.) Frank Majewski. Dr. Majewski was a tireless clinical researcher working with children with fetal alcohol syndrome at a time when there were only a handful of us in the world. In the early 1970s he published with Dr. Biericht, who published the first paper from Germany identifying children with Fetal Alcohol Syndrome. Majewski rather quickly accrued a large sample of children with "Alcohol Embryopathy" as he termed Fetal Alcohol Syndrome. In order to produce a quantifiable scoring system and improve the reliability of the diagnosis, he developed a weighted checklist of symptoms. He hoped this would make the diagnosis more accessible. He published much of his work in German, but the importance of international communication in those early days of alcohol research motivated the National Institute on Alcohol Abuse and Alcoholism to provide a free translation service for important documents, so we in Seattle were able to keep abreast of his work.

One of Dr. Majewski's most important studies began with a

large group of alcoholic mothers whose children he studied. He concluded that the more severe the mothers' alcoholism, the more severely affected were the offspring. In 1980, when we organized the first international workshop on Fetal Alcohol Syndrome, held here in Seattle at Battelle, we finally had a chance to meet.

I remember our amazement as we watched each other's slides of babies and children—diagnosed in different countries, retaining some national characteristics, yet looking so much alike as a result of their common intrauterine experience with alcohol. I can still see the blond, fair-skinned children from Germany and Sweden, the swarthy, dark-haired ones from Brazil. Frank brought his wife, Brigitte, also a pediatrician, to our meeting in Seattle, and we all met again when Frank and colleagues organized another international FAS conference in Frankfurt.

Frank made many important contributions to the field; his intensity and his passion for Fetal Alcohol Syndrome will be sorely missed. He is survived by Brigitte, three daughters and their families, and others. ♦

*Ann Streissguth, Ph.D., is a founding member of the Iceberg editorial board and director of the Fetal Alcohol & Drug Unit at the University of Washington in Seattle.*

###  
**short pull quote**

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## Finding support for FAS treatment

by Claire D. Coles, Ph.D

**B**oth parents and professionals often find it difficult to access resources for diagnosis of and treatment for alcohol-affected individuals. Very often private insurance or Medicaid does not cover all the diagnostic activities that are appropriate in understanding the effects of prenatal alcohol exposure. Even when diagnoses are made, insurance plans may not cover educational and therapy services that would

**Educational services, the most significant need for families of school-aged children, were not covered by any provider.**

be appropriate and patients may not qualify for existing special education categories in early intervention or special education programs. Without understanding of the individual's specific problems and appropriate treatment, the effects of prenatal exposure can be aggravated and develop into functional deficits and the secondary disabilities so well described by Ann Streissguth and her colleagues in 1996.

In 1993, we established a FAS clinic that provided differential diagnosis and treatment recommendations for children (0 to 21) suspected of having FAS and related disorders. At that time, the clinic was supported by the Marcus Institute general funds and by reimbursement from Medicaid and other insurance carriers. More than 80 percent of those applying for services from all over Georgia and the southeastern United States

were receiving Medicaid, either as their primary or secondary insurance.

By 1999, it became evident that the FAS clinic could not continue as initially established. There were two main problems. First, reimbursement did not cover the costs of staffing the clinic. The extensive genetic examination by the pediatrician was treated by the insurance carriers as a pediatrician's office visit, which was not adequate to pay the physician. Medicaid reimbursement for the speech, occupational and physical therapy was so low that we were unable to hire professionals to perform these services. Social work services, which were vital to families involved in foster care and adoption, were not sufficiently reimbursed. Psychological services were supported, in part, by volunteer professionals. A second problem was that some services were not covered at all. This was particularly an issue for educational services, probably the most significant need for families of school-aged children, which were not covered by any provider.

We turned to the Georgia State legislature. Several of the legislators, in the House and the Senate, were responsive when we explained the problems the clinic faced, and two agreed to act as "point persons" in getting a line item in the State budget to support the clinic. We prepared a budget and provided an explanation of our \$108,000 request for the 2001/2 fiscal year. We asked parents in the FAS Support Group to "tell their stories" during a visit from two of our representatives to the FAS clinic.

Others contacted their own legislators either in their home districts or at the state capital in Atlanta. We made sure that a delegation of parents and professionals visited the head of the House Appropriations Committee to discuss the proposal and sent professionals and families to speak at the Human Development subcommittee meeting. A parent delegation also visited the head of the Senate Appropriations Committee to discuss their children's special needs. At the same time, we conferred with the Department of Human Resources about the special needs of alcohol-affected children.

The requested funds were approved and included in the State Budget and we received funding in July 2001. Fortunately, the Department of Human Resources, acting on a request by Peter Fanning, Ed.D., president of the Marcus Center, determined that the FAS clinic qualified for matching funds from Medicaid designed to provide special needs children with services that were not otherwise covered under existing criteria. This approval effectively doubled our funds for this fiscal year and allowed us not only to survive, but also to greatly increase the range of services provided to affected children and their families. ♦

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*Claire D. Coles, Ph.D., Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine and the Marcus Institute, Atlanta, Georgia. For more information, call 404-727-9467 or e-mail [claire.coles@marcus.org](mailto:claire.coles@marcus.org).*

## **On-site Consultations: Preventing Prenatal Exposure to Alcohol**

**February – June 2002**

- Ontario, Canada
- Contact: Wendy Burgoyne,  
705/856-2997; fax 705/856-1320;  
[wendyb@beststart.org](mailto:wendyb@beststart.org)

## **A Lifetime of Solutions**

**May 8 – 10, 2002**

- Whitehorse, Yukon
- Contact: 867/667-3010;  
fax 867/667-3096;  
[jennifer.schneider@gov.yk.ca](mailto:jennifer.schneider@gov.yk.ca) or  
[patricia.living@gov.yk.ca](mailto:patricia.living@gov.yk.ca)

## **National Training Session Healing Hearts: SIDS & FAS/E**

**June 13 – 16, 2002**

- Kahnawake, Quebec, Canada
- Contact: 800/632-0892 ext-22; fax  
866/281-2014; [judij@niichro.com](mailto:judij@niichro.com)

## **Conference for individuals with FAS/ARND and their support person(s)**

**August 18 & 19, 2002**

- Grand Rapids, Michigan
- Contact: Barbara Wybrecht,  
[bmwybrecht@netzero.net](mailto:bmwybrecht@netzero.net)

## **International FAS Awareness Day**

**September 9, 2002**

- Contact: Bonnie Buxton or Brian  
Philcox, 416/264-1652; fax  
416/264-8222; [ogrady@pathcom.com](mailto:ogrady@pathcom.com)

## **Reclaiming Our Voices 4**

**October 16-18, 2002**

- Contact: Kathy Jones, 204/985-4061;  
[kathy@wrdfs.mb.ca](mailto:kathy@wrdfs.mb.ca)

*If you know upcoming events our readers  
may want to know about, e-mail us at  
[iceberg\\_fas@yahoo.com](mailto:iceberg_fas@yahoo.com).*

## Support groups listing online



It is difficult to keep parent support group information up-to-date with quarterly issues of *Iceberg*. Therefore, we refer you to an international list maintained online at [depts.washington.edu/fadu/Support.Groups.html](http://depts.washington.edu/fadu/Support.Groups.html). Please e-mail [fadu@u.washington.edu](mailto:fadu@u.washington.edu) or contact Katy Jo Fox at 206/543-7155 if you would like to add or update a listing or to request that a printed list be mailed to you. ♦

## Article submissions welcome

*Iceberg* welcomes article contributions from parents, professionals, and others with stories to tell about fetal alcohol syndrome. To submit an article, please follow the recommendations below.

To submit an article, simply e-mail it to [iceberg\\_fas@yahoo.com](mailto:iceberg_fas@yahoo.com), or mail it to *Iceberg*, P.O. Box 95597, Seattle, WA 98145-2597.

Please indicate whether the article has or might appear in other publications in the proximate six months period from your submission date.

The *Iceberg* editor reserves the right to shorten or alter any submissions for publication within the bounds of accuracy and the author's intended meaning without notice to the author. ♦

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