



# Living With FASD

Fall 2005

Saskatchewan Fetal Alcohol Support Network Inc.

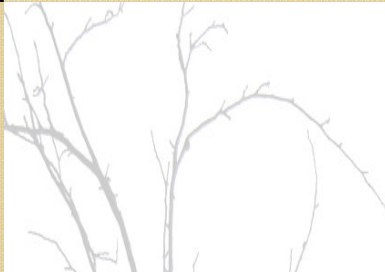
Celebrating the Diversity of Living with FASD

Interview with Krystle Pederson

Self Forgiveness

we CARES: A National Project

What is a Mentor?



# Saskatchewan Fetal Alcohol Support Network



## **syn·er·gy n.**

The interaction of two or more agents or forces so that their combined effect is greater than the sum of their individual effects. Source: The American Heritage® Stedman's Medical Dictionary Copyright © 2002, 2001, 1995 by Houghton Mifflin Company. Published by Houghton Mifflin Company.

There is a definite synergy within the Saskatchewan Fetal Alcohol Support Network these days. The members of the board, along with the staff of the Network, have been hard at work and it is true, when efforts are combined, great things can happen. Allow me to introduce you to the members of our board of directors and the staff of the Saskatchewan Fetal Alcohol Support Network.

## ***Board Members 2005-2006***



*Back row* Members at Large: Marilyn Macdonald, Shelley Kolisnek, Sylvia Nagy, Sandy Overs, Rae Mitten, Sarah Guenther. *Front row*: Past President Jonina Male, President Marion Tudor, Treasurer Terry Hellquist. Missing: Kim Skidmore.

The Saskatchewan Fetal Alcohol Support Network has been involved in a variety of projects since being formed in 1991. As the organization continues to grow, so too have the successes. This is due to the dedication and willingness of board members to work together to further the vision of the Saskatchewan Fetal Alcohol Support Network.

Together, members of the Board of Directors have knowledge, experience, and a willingness to contribute to their home communities. They are among the busiest people I have encountered.

## ***Staff Updates***

Eunice Bergstrom continues her role as the Project Developer for the Supported Housing Project for Persons with FASD. Eunice is a benefit to the Network as she is always willing to generously share her wisdom and insight. For an update and overview of the Supported Housing Project see the story on page 7. Contact information: 975-0896 Email: skfasnetwork2@sasktel.net



Beverly Palibroda is employed as the Communications and Research Coordinator for the Saskatchewan Fetal Alcohol Support Network. She works hard to represent the Network through her efforts with the *Network News* and *Living with FASD* publications. Contact Information: 975-0806 Email: skfasnetwork@sasktel.net



## ***A Note from the Executive Director***

Greetings to all!

Allow me to introduce myself. My name is Angela Schmolke and I am the Executive Director of the Saskatchewan Fetal Alcohol Support Network.

I am very excited about my role with the Network and about the work that we are doing to improve the quality of life of those affected by Fetal Alcohol Spectrum Disorder in Saskatchewan.

I hope that I will have the opportunity to meet many of you through various Network activities and would encourage you to contact the office to discuss with me issues around FASD that are important to you!

Together we can make a difference!

Contact information:  
Toll free: 1-866-673-3276 (FASN)  
Saskatoon: 975-0884  
Email: fasnnetwork@sasktel.net



*Living with FASD*



# President's Message

Marion Tudor



## Helpful Little Sayings

I've been reminded of a couple of little sayings this summer that most of us have probably used from time to time...

I traveled to Britain during June and July to spend time with family and have a vacation. We were staying in London just before our return trip home. I was on the Tube on my way to say goodbye to my parents at the time of the bombings. In fact, I was just a few minutes away from Kings Cross Station. I didn't know what had happened; none of us did at that time, but about 300 people had to leave the train and the station and find another way to continue their journey. That many people, milling about and not knowing where to go, most using cell phones, was rather overwhelming.

Fortunately, I grew up in London and was able to find a way to get back to where I came from. It was quite unsettling, though, not knowing at first, which bus to take, or whether there would be anyone at my mother-in-law's home when I arrived, since the expectation was that I would be away until evening.

It wasn't long before I had a 'plan B' in place (if no one was home, I'd drop a note through the mailbox and wait at the library), and what a relief that was. I also started thinking about how fortunate I was because, it could have been worse. I didn't have a large suitcase with me, I spoke the language, knew how to find and use a bus, and all those other things that could have complicated the situation.

This brings us to those two little sayings that I mentioned – 'Always have a Plan B', and 'Could be worse'! I think these are excellent sayings to remember when we are parenting children or adults with FASD. A 'Plan B' will relieve the stress if something doesn't go according to 'Plan A', and although we do experience some very difficult situations, it could almost always be worse (even though it may not seem like it at the time).

I hope that your summer was a good one and that transitions into fall routines go smoothly for you and your family....and have 'Plan B' ready in case they don't!

### Highlights of this Issue:

Circles of Support.....	4
Article Review: The Snowflake Book...	5
So Many Stories.....	6
we CARES: A National Project.....	8
Mentoring Persons with FASD.....	9
Self Forgiveness.....	10
Question and Answer.....	11

The Saskatchewan Fetal Alcohol Support Network would like to express our gratitude to SaskTel for providing assistance with the funding of our publication *Living with FASD*. It is through such arrangements that we are able to continue to provide news and information to our readers. Thank you SaskTel.



## Labelling – The Importance of Knowing

By Marion Tudor



A label can tell us what's in a jar. It can tell us where something was made, or how fresh it is. Sometimes we hear that we shouldn't label our children as having FASD. FASD is not a label – it's an important piece of information that can and should change the lives of our children and our families.

Many of our children are incorrectly labelled by their friends and themselves, when they don't know the reason for their difficulties. The label might be 'lazy', 'slow', 'bad', or 'stupid'.

When we share the knowledge that our children have FASD, and help others understand what that means, we can change those labels to positive ones. We need to get rid of the stigma that FASD seems to have, so that a child or adult with FASD is accepted in the same way as one with diabetes, Down's Syndrome, or Cerebral Palsy – all lifelong conditions that can and do have positive outcomes.

**FASD is not a label – it's an important piece of information that can and should change the lives of our children and our families.**



# FASD Support Network: Material Development



## *FASD Tips for Parents and Caregivers*

When it comes to looking for answers to parenting questions, parents of children with FASD may become discouraged when they find that the parenting information available does not work for their child. It can be additionally frustrating when others involved in your child's life do not understand that some traditional parenting or teaching strategies simply will not work because of the damage to the brain of a child with FASD.

In order to address this lack of information, The Saskatchewan Fetal Alcohol Support Network, with the help of experienced parents and caregivers, developed a set of FASD Tips. Currently, 16 FASD Tips for parents and caregivers are available to assist in supporting individuals with FASD. The tips are accessible on the Network website and can be printed and shared with family members, school personnel, medical professionals, or social workers. The information not only increases one's understanding of FASD, but also provides practical strategies that build on individual strengths. Persons with FASD can then experience feelings of success and not failure.

The most recent titles added to the FASD Tips for Parents and Caregivers are now available. Titles include, How to help Children or Teens with FASD To:

- **Understand Structure**
- **Develop Routines**
- **Be Successful at Camp**
- **Succeed in Community Groups**
- **Understand Time**

## *Circles of Support*

Research shows that support is a key factor in successful family functioning. Families most often receive support from extended family members, community groups, or other informal arrangements. Some families require more specialized support than extended family and friends can offer. A community support group dedicated to a specific issue can fill this need. Several benefits of support groups have been identified:



- Learning new strategies
- Developing coping skills
- Relief from isolation
- Sharing of experiences
- Working through emotions such as feelings of grief and loss ([www.supportfind.com](http://www.supportfind.com))

Individuals may experience other benefits as well, based on their unique experiences.

Imagine coming together with a group of people who understand the joys and challenges of parenting or caring for a person living with FASD. Imagine having a group of people who are willing to listen to you, not judge you, and are there to guide you as you do your best to understand just how FASD has influenced you and your family. In the near future the Saskatchewan Fetal Alcohol Support Network will begin delivering support groups for parents and caregivers of persons affected by FASD. Thanks to generous funding through the Regional Intersectoral committees in Saskatoon and Regina, we are able to begin this pilot project. Watch for announcements in upcoming issues of *Network News*, or contact the Network office.

## *Parent Support Group Manual*

In addition to the development of support groups in Saskatoon and Regina, the Network also has a support group manual available through the office for a fee of \$10.00.

The Support Group Manual has been designed to help community members in their efforts to start and maintain a parent's support group. The manual includes ideas for gathering interested individuals, how to plan an agenda, a list of suggested discussion topics, resource lists, and copies of Network materials for distribution to group members.

The Network is willing to provide guidance in the development of support groups and will certainly learn more as the pilot projects in Saskatoon and Regina progress.



## *FASD Tips in French*

The FASD Tips for Parents and Caregivers are now available in French. Please contact the office to request a copy. If you know of a family, organization, school, or community group that could benefit from French Language FASD information let them know about this great resource. See page 12 for contact information.



# Articles, Resources, and Websites



## **Article Review: The Snowflake Book**

Jocie DeVries  
F.A.S. Times Fetal Alcohol Syndrome/  
Family Resource Institute Newsletter  
Winter 2004/2005  
Review by Beverly Palibroda

The author of *The Snowflake Book*, is a mother of three children. She describes herself as “the family advocate” but goes on to explain the difficulties of advocating for her children and trying to educate professionals such as doctors, teachers, counsellors, police, and judges around the issue of FASD.

As with many parents, she has done her research. She found herself in the awkward position of being better informed about FASD than those professionals in her life assigned to help her and her family. How then does a parent with the knowledge and information share this with professionals and advocate for a child with FASD? How do you share the research that you have done, the experiences you have had, and the documents gathered?

The author outlines how to create a practical resource that can readily be developed and changed according to the needs of the individual. She came to refer to the collection of information she gathered as the Snowflake Book, because like snowflakes, no two of us are alike, and therefore no two books will be quite the same.

A Snowflake Book is essentially a book with documentation related to your child and FASD. The author recommends using a three ring binder with plastic pocket pages to contain the materials gathered.

Again, the information will differ from one family to another, and this idea can be readily adapted to meet specific needs. The recommended organizational structure is to arrange the information into three divided sections, as follows:

### **Section 1**

Include copies of items such as:

- Diagnosis
- Assessments
- Medical reports
- Neurological Evaluations
- School documentation and report cards
- Letters of support from professionals
- Counsellor’s notes

### **Section 2**

Include theoretical information and research based materials:

- Journal articles
- Research papers
- Resources available
- Suggested reading lists
- Brochures

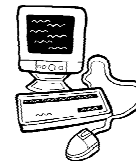
### **Section 3**

Include information from mainstream publications, support groups, community organizations, or personal stories:

- Newspaper articles
- Magazine articles
- Online stories and documentation
- Interventions and strategies for parents, teachers, or individuals with FASD

An organized book of documentation is a very useful and practical tool. It seems a very basic idea, but perhaps it is one that busy parents may not have thought of, or taken the time to put together. The resource book will not only give families the tools to better advocate for their child, but will also help to inform others about FASD and how they can use the knowledge to better serve persons with FASD.

## **Virtually Speaking**



Time spent wandering the World Wide Web can provide a wealth of information. It can be something of a treasure hunt, without

the map to guide you. The following websites are treasures that I came across and have included because they offer access to information and resources, that will be of interest to SFASN members.

### **Better Endings [www.betterendings.org](http://www.betterendings.org)**

This site offers an excellent source of information. A most interesting resource is a downloadable Grief Workbook. The workbook has been designed for teens or young adults with FASD who are facing situations causing grief. The lessons are interactive and have been designed by Jodee Kulp, a parent of a young woman with FASD, and a well known author.

### **Journal of FAS International [www.motherisk.org/JFAS/](http://www.motherisk.org/JFAS/)**

This site is dedicated to FASD and is the official journal of the FACE (Fetal Alcohol Canadian Expertise) Research Network.

The site offers the journal at no cost to the reader and includes online scientific and research articles as well as more informal commentary pieces.

# Provincial FASD News and Research



## *So Many Stories*

We have an abundance of talented and creative individuals within our province. It might be the vast skies, open spaces, or encouraging community of people that spur on our creative urges. Whatever the source, it is certainly a reason to celebrate. The Dancing Sky Theatre, based in Meacham Saskatchewan, embarked on a traveling theatre production this summer supported by Saskatchewan Centennial 2005. The production was staged under the vast open skies and the cast was indeed talented.

Respected writers, Maria Campbell and Trevor Herriot, creatively led this one-hour theatrical production. Based around the principle that the one thing Saskatchewanians share and love is the place—the land that we call home, the production tells a story that is poignant and enjoyable for all ages. ([www.sask2005.ca/new/theatre\\_tour.asp](http://www.sask2005.ca/new/theatre_tour.asp)) Just as we rely on this land, we also rely on each other and each of us has our own story. This production explores these themes in a sometimes-playful way, but in turn challenges us to look for a deeper meaning in our interconnection with each other and with the place we call home.

The theatre production visited numerous rural communities throughout Saskatchewan. I had the opportunity to enjoy the production under the open skies and near the healing waters of Manitou Beach in south central part of our province. The evening was warm, with a slight breeze, and the crows were calling in the background. It seemed so

fitting for the melodic voice of a young woman, Krystle Pederson, to join with the sounds of the evening. I was fortunate to have the opportunity to chat with Krystle. Krystle was raised in Martensville, SK. She was adopted as a young girl and has since been identified as being affected by prenatal maternal alcohol use.

Krystle and I chatted about a number of items; she shared her enthusiasm and passion for her singing and work in the theatre, and we also explored some of the struggles she faces as a young woman in a complex world, and how her life is affected by FASD.

Showing a mature attitude, Krystle explained that she does not want to use FASD “as an excuse to fail, but as a reason to succeed.” Like many young people affected by FASD, school was difficult for Krystle. The academics were problematic, as were the times when others teased and picked on her. She was in a situation where she felt she always needed extra help, from teachers and counsellors and that she could not succeed on her own. Singing was something she could do on her own and she found that success and feeling of accomplishment that we all need, especially during our teen years. Krystle identifies that “singing helped push me forward” and “singing helped keep me strong.” Clearly, having an avenue to be successful in her teen years has helped her to face the struggles and difficulties and the feelings of success have meant a lot to her.



Family support has been vital to Krystle. She shares that her mom has been there for her as a support and that her mom has helped her learn strategies to overcome some of the effects of FASD. I found Krystle to be very insightful and honest about some of the problems she has relating to others. She

claims to experience personality clashes, frustrations, and difficulties due to keeping things “bottled up” and then saying things that she doesn’t mean to say. What she has found that works for her is for people to be open and honest with her when she is not relating to them well, or when she appears to be struggling with her people skills. Krystle is very aware that as she enters her young adulthood, her mom won’t always be there, and that she will need to use strategies to address her problems, and that she may need to open up to others and enlist their support. As we finished our conversation, I felt encouraged that this young woman has found a creative outlet; she has found her gift and a means of feeling successful. I told her, “Krystle, I will be cheering you on!”

### ***Project Hope Revealed***

On August 4 Graham Addley presented *Healthy Choices in a Healthy Community*, to the public. In response, the Premier unveiled Project Hope. Project Hope is based on the research and recommendations of this report. Full copies of Saskatchewan’s Action Plan for Substance Abuse and Graham Addley’s report *Healthy Choices in a Healthy Community* are available online at [www.publications.gov.sk.ca](http://www.publications.gov.sk.ca).

# Provincial Interagency and Community Activities



## *An Update on Supported Housing*

A year has gone by since the beginning of the Supported Housing Project for Persons with FASD. Eunice Bergstrom, along with the steering committee, has accomplished a great deal during this time. A key component of the project has been the provision of educational sessions. Through the education and information sharing with government and community organizations, the profile of FASD has been raised, as well as the level of knowledge and understanding of FASD within Saskatoon.

All of this could not have been accomplished without the commitment and coming together of so many people from various sectors. The unfolding of the Supported Housing Project has been a process that has allowed us to feel hopeful and encouraged for the future of persons with FASD and their families. For more information call Eunice at 975-0896.



## *The Speakers Bureau: A Community FASD Partnership*

Through shared effort, the Saskatchewan Prevention Institute and the Saskatchewan Fetal Alcohol Support Network offers the services of talented speakers from regions across the province. The speakers have access to a range of resources and can tailor their speaking engagement to the needs of the group.

Speakers are qualified to present on topics such as: information and awareness, primary prevention, parenting or classroom strategies, prevention of secondary disabilities, or specific topics as requested. To book a speaker call 655-2312.

## *Community Awareness and Action leads to Safer Communities*

The Saskatchewan Fetal Alcohol Support Network has completed a series of Community Awareness and Action Workshops held throughout the province. The presenter, Dr. Mavis Olesen, received excellent reviews. Participants found her to be knowledgeable, approachable and always willing to respond to questions.

The focus of this project was to reach family members, professionals, and community members who were willing to participate in a workshop and go back to their communities to engage in personal or collective action related to FASD and crime prevention. Participants were provided with a resource, information, ideas, and the support needed to implement their action plan based on crime prevention related to persons with FASD. With funding provided through the Community Mobilization Program of the National Crime Prevention Office, over 350 individuals were able to take part.

The project was designed to address the impact that FASD has on the communities when secondary disabilities related to FASD are not dealt with effectively. The project specifically addressed the protective factors required in order to reduce the involvement of persons with FASD in criminal activities. Though certainly not all persons with FASD become involved in crime, it has been identified that persons with FASD become involved in crime, either as a victim or perpetrator, at high rates.

By stressing both the awareness and action of community members, crime can be reduced, the communities can be safer, and individuals with FASD will have the opportunity to live healthy and productive lives.

## *Battlefords FASD Interagency Committee News*

Submitted by Colleen Sabraw

The folks in the Battlefords district will be busy this fall. They have planned a variety of activities, most scheduled during the week of FASD Day or the week following. To mark international FAS day they are having a moment of silence and proclamation signing on September 9th at City Hall. Other activities include a coloring contest, an FASD Quiz on local radio stations, and an FASD awareness campaign that includes the printing and distribution of promotional materials to all liquor establishments in the area. Establishments will also provide free non-alcoholic drinks for pregnant women. Finally they will host educational sessions and an FASD conference on October 20th. For information contact Colleen Sabraw at [becip@sasktel.net](mailto:becip@sasktel.net).

## *Prince Albert FASD Interagency Committee News*

Submitted by Dianne Nielsen

This summer has been slow for activities; however, people continue to use the FASD library. In addition, two more committee members have become we CARES Community Trainers, and they have been doing training sessions for staff at Prince Albert Correctional Center.

For FAS Awareness Day we have planned a march to bring recognition to FASD prevention and awareness that people in our community are affected by FASD. The march ends at the Friendship Center where participants can enjoy displays, a door prize, and lunch. We will also have a poster contest, media information, and information packages mailed out to interested individuals. Please contact Dianne Nielsen at [pacada@sasktel.net](mailto:pacada@sasktel.net).



# National FASD News and Research



## *we CARES: A National Project*

By Beverly Palibroda

Over the past 4 months there have been waves of activity throughout Canada as the we CARES project has been underway. The we CARES project is a model of training front line support persons to gain the practical skills necessary to provide appropriate guidance and mentoring to youth and adults affected by FASD. The we CARES project is based on the train the trainer model. Master Trainers receive intensive training and education on the we CARES model and philosophy of support, and then in turn go to communities throughout the region to provide training to community trainers. The community trainers are then required to provide educational sessions to others within their community. The train the trainer model has been well received and used in other community development initiatives.

Ten master trainers received training in the spring of 2005, and since then have been conducting the community trainer workshops. In Saskatchewan we have held workshops in Prince Albert, Saskatoon, and Regina. The third location, Regina, funded through Saskatchewan Health, was added to the sessions as we had an overwhelming number of applicants. Over 100 community trainers attended the sessions and will be conducting sessions throughout the province. Participants from all areas of the province attended, including Sandy Bay, La Loche, Moose Jaw, and Fort Quapelle. Master Trainers, Mavis and Jim Olesen, presented in Alberta, Saskatchewan, and Manitoba.



*Mavis and Jim Olesen demonstrate the effect of alcohol on a raw egg.*

The we CARES philosophy is based on strategies that correspond to the acronym CARES: **Cues, Attitude, Repetition, Environment, Structure and Supervision.** The acronym CARES is an effective tool that allows family members, caregivers, and support persons to quickly recall the model of support and apply the ideas to whatever situation they may encounter with a person with FASD. This model of support has been implemented in a supported housing facility in British Columbia, to much success. Those in the circle of support are reminded to use verbal, visual, and concrete cues in our interactions. In addition, and perhaps most importantly, we are encouraged to examine our own attitudes and reflect on how our attitude is influencing the life of a person with FASD. The use of repetition, changing the environment, structure and supervision in the lives of persons with FASD are strategies that have proven effective for many families.

*The we CARES manual was developed by the group Anne Wright and associates. It is available online: [www.annewrightandassociates.ca](http://www.annewrightandassociates.ca)*

## *we Cares Community Trainers are Available in a Community Near You*

Chances are high that someone in or very near your community has received their we CARES Community Trainer Certification. The trainers are ready, willing and able to come out to share what they have learned. We at the Network are proud of our involvement in this project and would encourage groups and organizations to take the opportunity to book a Community Trainer.

While the training has been designed specifically to address issues around homelessness, the information can be tailored to meet the needs of a variety of audiences. Trainers could attend events such as staff in-service meetings, staff development days, community service-group meetings, or informational workshops for the general public.

The we CARES information would be useful to a variety of persons including: students (social work, youth care, rehabilitation, recreation), staff of supported housing facilities, vocational centres, youth organizations, mental health facilities, addictions facilities, health centres, supported employment programs and individuals from corrections or police services.

To be connected with a we CARES Community Trainer, or to find out more about booking a Community Trainer, contact the Network office; see contact information on page 12.

**Our hope lies in the ripple effect**

**10 Master Trainers  
19 Communities  
380 Community Trainers  
7,000 service Providers**



# National FASD News and Research



## *Mentoring Persons with FASD*

By Beverly Palibroda

As my mother in law patiently explained what to look for when picking mushrooms, and pointed out the mushrooms for me to pick, I felt grateful for her guidance. I was told you need to “develop an eye for mushrooms, and that takes time.” This got me thinking about the notion of mentoring. I had just attended the we CARES workshop in Prince Albert, and the topic of mentoring kept coming up. I thought about all the times when my mother in law gave me that extra word of encouragement when I felt alone, listened while I explored life’s mysteries, helped me determine what was right and what was wrong, or shared her experiences and understanding of life. She probably would not accept the title of mentor, but that is what she has been for me.

Each one of us requires guidance and support in our lives and the guidance of a mentor is a wonderful experience for both involved. Persons with FASD require guidance more often and will require a level of guidance that is more structured and long term, than those unaffected by FASD. Persons with FASD very much need and deserve to have the experience of a mentor in their lives.

Young children living with FASD quite naturally receive support. Perhaps not as much support as they require, but the chances that parents, caregivers, family members, educators, coaches, and school peers are in their circle of support is greater than that of teens and adults with FASD.



As a child with FASD becomes a teenager, the need for guidance actually may increase yet the guidance and support received often decreases. Reasons for this vary, but it is likely that those within that youth’s circle have changing expectations. The coach or educator may be less willing to provide direction and guidance in decision-making and problem solving. Others may not understand that FASD is a lifelong disability and that life lessons need to be learned over and over again. The youth herself has changing needs and expectations. She witnesses her peers gaining autonomy and making decisions. She too wants this for her life; she wants some independence from her family. Peers may not have the knowledge or skills to provide continued support for their friend affected by FASD, in part because the issues faced often become very serious. Youth are faced with issues such as violence, substance use, sexuality and dating. Risk taking behaviours are not uncommon with adolescents; an adolescent with FASD is no different.

By the teen years, stress and frustration may be taking its toll on parents, family members, and caregivers. They may be less resilient and feel that they have tried everything and have no answers, thus the level of support decreases. It is also likely that they receive conflicting messages from professionals, and feel high levels of confusion about how to best guide their child.

This is where a mentor could very well make all the difference in the life of a person with FASD. A mentor is a person who is willing to care about, guide, and support a young person with FASD. Mentors share in the life of the young person, they provide opportunities to experience, learn, make decisions, and make mistakes, all in a supportive and encouraging relationship.



The mentor can be a valuable asset to the circle of support of a young person with FASD. The mentor does not replace other members of the circle of support; a mentor becomes one of the people in that circle. This is important for both the youth with FASD, and the parents or caregivers. The parents must recognize when they need to step back and allow others into the life of their child. The parents will of course stay involved, but for the best interests of all involved, including the parents, stepping back is a wise idea.

Characteristics of successful mentoring relationships have been identified. Longer mentoring relationships, frequent contact, activities guided by the youth’s interests, and the development of a relationship with the family members are all factors that are shown to lead to outcomes that are more successful. (Jekielek, S. Moore, K., Hair, E., Scarupa, H., *Mentoring: A Promising Strategy for Youth Development*. 2002)

Of course, not all mentoring relationships work and the identified reasons for failure are “lack of program structure, lack of training and supervision for mentors, [and] a lack of commitment.” (Jekielek, S. Moore, K., Hair, E., Scarupa, H., *Mentoring: A Promising Strategy for Youth Development*. 2002). Clearly mentoring is an important and worthwhile venture. There are many areas yet to explore and questions left unanswered, however, mentoring seems to be a strategy that could make a real difference in the lives of people with FASD.



# International FASD News, Research and Stories



## Self-forgiveness

By Mercedes Alejandro

Forgiveness is learned early in life when, as children our parents overlook an offense or forgive our breaking an expensive or beloved object. They are the first to teach us how it feels to receive loving forgiveness and unconditional acceptance from those we hold dearest. We learn that we can begin again with a "clean sheet." We also learn from our church, temple, or synagogue that God forgives and nothing brings us closer to Him than acknowledging our sins, faults, and shortcomings.

My first experience in self-forgiveness was at the tender age of 26, walking home from work, deep in contemplation and regret at my failed marriage and seeing, in retrospect, all the signs that this marriage was the wrong choice for me. My thoughts turned to other friends who had also divorced and I evaluated in my mind which of the two was at fault. In my thoughts I realized that both were at fault and that we all make mistakes.

This last thought "we all make mistakes" kept playing over and over in my mind. At last a light bulb went off in my mind as I concluded that, if we can forgive others for their faults, surely we can forgive ourselves! I knew the failure of my marriage was also my fault and decided at that mo-

***Forgiving yourself for having caused your child's disability is the first and most important step towards healing your heart...***

ment to forgive myself and stop beating myself up over it.

Years later when I attended a conference for families of children with disabilities, I sat in a session describing developmental delays in children (where I first met Dr. Clayton). It seemed they were describing my own child item by item. However, the description was of a child born with FAS/FAE. I went over in my mind over and over again my pregnancy and realized that I did drink while I was pregnant. But it had never before occurred to me that I could have caused my child's developmental delay.

Once again I was faced with guilt, regret, anger, and denial over how my child had gotten such a

slow start in life. It was certainly not his fault, and it was not a childhood he deserved. Finding out that in all probability I had caused it could have devastated me and paralyzed me emotionally.

As his mother, I had to make a conscious decision to either wallow in guilt and despair or face it head on and deal with it. I had caused in my child a preventable disability! Of course the first step, hard as it was, was to forgive myself, I had made a very serious life-altering mistake. One my child and I both had to live with. But there was no going back in a time machine to undo

the damage and there was no point in punishing myself.

Once I decided to forgive myself (whether others did or not was not important) in order to go on with my life and my son's, I came to the following conclusions:

1. I am lucky because some parents never find out what caused their child's disability and just knowing he has FAS/FAE gave me a tool for seeking therapy and educational approaches that address his specific strengths and needs;
2. I became an advocate for my son at school and in our neighborhood, opening doors for his success in education, employment and in life;
3. I decided to get used to glances from people who invariably judge and blame me for a mistake I made many years ago. I decided their opinions would be only that, "their opinion" because I had already forgiven myself; finally, I sought out parent support groups so that I could get the strength, understanding, and acceptance I need. Parents who raise children with Fetal Alcohol Syndrome or Fetal Alcohol Effects, learn to understand and accept our children just as they are and for what they can become.

Forgiving yourself for having caused your child's disability is the first and most important step towards healing your heart and will free you for the task at hand -- raising this wonderful special child.



### United Kingdom

"Public-health problems associated with alcohol consumption have reached alarming proportions, and alcohol has become one of the most important risks to health globally."

<http://www.fasaware.co.uk/news.php>

### The Netherlands

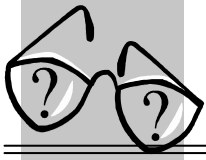
In November of 2004, the Netherlands FAS Foundation launched a newsletter targeted at parents and those who work regularly with children with FAS.



### South Africa

The Pebbles Project is in the works. The project vision is to: enrich the lives of children from disadvantaged backgrounds with special educational needs, especially those affected by alcohol, through providing support and training to local crèches and primary schools.





# FASD: Questions and Answers



**Q. I have heard that children with a Fetal Alcohol Spectrum Disorder often experience sensory integration problems. What does this mean and how do I know if my child might be having this problem?**

Response By Lisa Brownstone

**A.** The five senses all work together to give us an accurate picture of our environment, who we are, and how we move and act. When the senses work well together (and this is often automatic) it is called sensory integration. We need to integrate all our senses for the complex learning and behaviours that are part of our lives.

For some people, sensory integration does not automatically evolve. The process of integrating sensory information becomes disordered, leading to problems in learning, behaviour and development. This is called sensory integration dysfunction.

**Some signs of sensory integration problems are:**

- Overly sensitive, or under sensitive, to touch, movement, sights or sounds
- Physical clumsiness or apparent carelessness
- Difficulty making transitions from one situation to another
- Delays in speech, language or motor skills

Sensory integration dysfunction can be hard to pick up. The following example shows the soft signs that were picked up by one family. The baby did not like being touched for any length of time, touch had to be firm, as opposed to soft touch or stroking. When she began eating solids, she separated out her food, and did not like certain textures, or food with much spice. She was always cold.

Once the family becomes concerned, sensory integration dysfunction must be assessed, and properly evaluated by an occupational therapist. Sometimes other therapists also provide evaluations. The evaluation should consist of a thorough history, standardized testing and structured observations of the responses to sensory stimulation and balance, posture, coordination and eye movements. The results will be analyzed and the therapist will guide the child through a series of therapeutic activities. Depending on the child, results can be dramatic and well worth the attempt.

For further information please contact Sensory Integration International at [info@sensoryint.com](mailto:info@sensoryint.com), or write to Sensory Integration International at: P.O. Box 5339, Torrance, CA. 90510-5339.

The Saskatchewan Fetal Alcohol Support Network would like to extend our gratitude to Lisa Brownstone for her response to this question. Lisa is trained as an occupational therapist and has a wealth of professional and personal experience. She recently completed a Housing Feasibility Study for People with FASD. A copy of the final report can be obtained through the Network office or is available by contacting Lisa through email: [lbrownstone@sasktel.net](mailto:lbrownstone@sasktel.net).

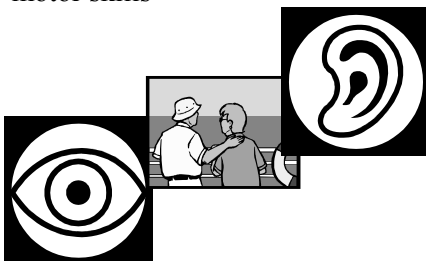
***Did You Know?***

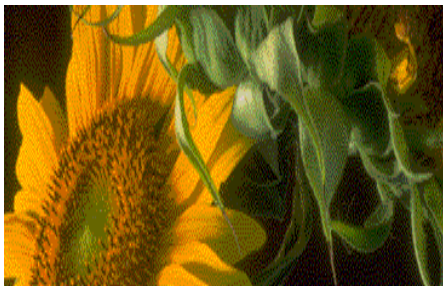
The Network has a Tip for Parents and Caregivers titled: How you can Help a Child with FASD Learn to Cope with their Senses  
For a copy visit our website at [www.skfasnetwork.ca](http://www.skfasnetwork.ca)

Disclaimer: *Living with FASD* offers this question and answer column as general information. It is not intended as a substitute for professional advice on medical, behavioural, educational, or legal matters. The responses, when not reprinted from acknowledged sources, are provided by members of the Saskatchewan Fetal Alcohol Support Network and are the opinions of those members based on their experiences as parents and caregivers of people with FASD. If you have a question, contact the Network office; see contact information on page 12.

**Live your questions now, and perhaps even without knowing it, you will live along some distant day into your answers.**

Rainer Maria Rilke German lyric poet (1875 - 1926)





# Upcoming Events



Contact the Network for event details

## Saskatchewan Fetal Alcohol Support Network Inc.

John V. Remai Centre  
510 Cynthia Street  
Saskatoon, SK  
S7L 7K7

Toll Free: 1-866-673-FASN (3276)  
In Saskatoon: 975-0884

fasdnetwork@sasktel.net  
www.skfasnetwork.ca

The vision of the Saskatchewan Fetal Alcohol Support Network, a parent-led organization, is for individuals with Fetal Alcohol Spectrum Disorder and their families to recognize themselves as safe, supported, valued and contributing members of the community.

To reach this vision we provide support to people with Fetal Alcohol Spectrum Disorder, their families and circles of support by:

- Providing information and education
- Promoting early assessment, diagnosis and intervention
- Advocating for the development of life-long support services for individuals with FASD
- Establishing partnerships
- Working to increase awareness of FASD

The Network creates this publication, *Living with FASD*, as a benefit of membership. Memberships are available for \$15. Please contact the office to become a member.

**Living with FASD** Publication Committee  
Beverly Palibroda  
Shelley Kolisnek  
Jonina Male  
Kim Skidmore  
Sylvia Nagy



## Best Start Saskatchewan

October 26-28th, 2005  
Saskatoon, SK  
The goal is to advance awareness and knowledge about maternal and infant health and early child development. Of special interest is the session titled, Strengthening the Circle –FASD Prevention– Mentorship Pilot Project

**National Conference of the Canadian Association for Community Living** co-hosted by the Saskatchewan Association for Community Living  
November 2-4th, 2005  
Saskatoon, SK  
Advancing a Family Agenda to support Canadians with Disabilities.  
November 2 dedicated to the topic of FASD.

**National Supported Employment Conference**  
November 23-25, 2005  
Saskatoon, SK  
Hosted by Canadian Association for Supported Employment.  
The two day conference features over a dozen relevant topics on supported employment and how services to persons with disabilities can be enhanced.

**Training and Information Sharing Sessions**  
Supported Housing Project for Persons with FASD  
Fall and winter 2005—2006  
Call Eunice Bergstrom at 975-0896 for information.

## Article Submissions

The next issue of *Living with FASD* will be distributed in the Spring of 2006. The deadline for submissions is February 15, 2006. Personal stories, poetry, photos, article reviews, and research findings are all welcome. Please contact Beverly at 975-0806 with any questions you might have.

## FASD Centre Regina Community Clinic

FASD Lifeskills/Mentor services available. Contact Cheryl Charron 543-7880 ext.268  
FASD Employment Support Coordinator services available. Contact Shelley Brown 543-7880 ext. 233

## we CARES Workshops Facilitated by Community Trainers

Fall 2006  
Contact the Network office for details or information on booking a community trainer or to attend a workshop in your region of the province.

## we CARES Community Trainer Followup

A session for Community Trainers to gather and share experiences.  
November 2005 Details TBA.

## Canada Northwest FASD Partnership Conference

May 17-19th 2006  
Regina, SK

## Adults with FASD 2006

**Conference:** "Navigating the Rapids: Doing What Works In Practice"  
May 4th - 6th, 2006  
Vancouver, BC  
Sponsored by the University of British Columbia, Interprofessional Continuing Education and FASD Connections: Serving Adolescents and Adults with FASD.

©2005 Saskatchewan Fetal Alcohol Support Network. No portion of this publication may be reproduced in part or in whole without permission of the Saskatchewan Fetal Alcohol Support Network.



*Living with FASD*