

# The Family Connection

## FASD Family Support Group Meeting

**DATE:** Wednesday, June 25, 2008

**TIME:** 7:00-9:00 PM

**PLACE:** ECCPASA  
1625 Hertel Ave, Buffalo, NY  
(Between Parkside & Starin)

**TOPIC:** "Cutting through the red tape"  
Obtaining Appropriate State Services

**GUEST SPEAKERS:**  
Kevin Penberthy, Consumer Services  
Cindy Rathbun, Intake Coordinator

**WNY Developmental Disabilities Services Office (DDSO)**

**DON'T MISS THIS IMPORTANT MEETING!**

***Back by popular demand!***

We are very pleased that Kevin Penberthy and Cindy Rathbun of the Western New York DDSO will be our guests at this month's meeting on June 25. Mr. Penberthy was our guest two years ago and parents requested that we invite him to come again. Not only did he share a wealth of important information, but demonstrated a keen understanding of the specific issues related to helping obtain services for the child with FAS/FASD.

The goals of DDSO offices throughout the state are to improve the quality of life for individuals with developmental disabilities by providing housing, employment, and family support services. Although numerous valuable services are available through the DDSO, the "system" can be very confusing and overwhelming at times. Mr. Penberthy and Ms. Rathbun will be discussing what services are available, how to access these services, how eligibility is determined, and how FAS/FASD fits into the DDSO system.

### *A Letter From a Teenager*

On the back is a letter by a 16-year old that she wrote to help people better understand what it is like for her to have FAS. Writing can be a powerful tool to express feelings or frustrations and inform others about daily struggles. A letter from a teen may be shared with teachers, family members, and others.



Questions or suggestions? Call Helen at (716) 831-2298 or email [helenw@eccpasa.info](mailto:helenw@eccpasa.info)

# ***Fetal Alcohol Syndrome: A Letter from a Sixteen-Year-Old***

by Sidney Helbock



When I first found out that I had the symptoms of Fetal Alcohol Syndrome I was confused and angry. I thought that I was different from everyone else and that I would be known for what I have. Since then, I have learned that the symptoms vary from individual to individual. It depends on during what stage of the pregnancy the mother drank, and the amount of alcohol consumed.

One of my symptoms is trouble understanding instructions. When a teacher shows us a certain topic, I can understand. Visual contact is a very important way of learning for me. Instructions sometimes confuse me. Following instructions is hard. When I'm asked or told to do something (like "take out the garbage") I won't understand, or the words get all mixed up in my mind.

Some other symptoms are not being able to follow oral instructions as well as written ones (example—Teacher giving assignment instructions orally—not being able to remember or follow them correctly); not hearing exactly what is said to me (example—My stepfather giving me a command to do, and not hearing him clearly, even in the same room. It's like I don't catch some words or phrases); being impulsive, doing or acting on excitement, not able to focus on reality if disaster strikes.

Most of the time I worry a lot and make problems seem impossible to handle. When I worry, I make myself sick. At school sometimes I get sick to my stomach, or get a fever and feel awful.

These symptoms are very small compared to some symptoms I've heard of. Some people find it impossible to believe when I explain my problem, since they can't see the signs of FAS.

This letter is to help me guide myself and others. I want to help people learn about FAS, help parents who have kids who have it, and let other people who have it understand themselves better.

Sincerely,

*Sidney*

(This letter was written for *Iceberg* magazine)