

The purpose of this newsletter is to educate, inform, advocate, and empower people in order to affect positive change in attitudes and treatment for psychiatric illnesses.

## Are antidepressants worth the "risk"?

This inaugural issue is pleased to present an article by Pamela A. Campbell, MD., Associate Professor of Psychiatry and Pediatrics, Cincinnati Children's Hospital Medical Center. Since the flurry of media and professional attention to antidepressants' risks in young people, many parents are confused and anxious about starting or continuing these medications. As the information is often confusing and misleading, I would like to provide some background and facts and outline some guidelines for making a complex and possibly life saving decision.

The controversy began in 2003 in England when concerns were raised over some drug companies' failure to report negative studies. There were also concerns that certain adverse reactions, such as suicide, were not clearly indicated. An intensive review (see article on page 3) found that two percent of those taking the placebo reported the new onset of suicidal thoughts or attempts, while four percent of those receiving medication reported new suicidal thoughts or attempts. This is in a population of children/adolescents with depression, which is a known risk for suicidal thoughts. They are also asked repeatedly about

suicidal thoughts throughout the trial. Of note, there were no actual suicides among the 4100 participants. These numbers seem small and the difference even smaller, yet the real controversy among professionals is another set of statistics from the studies.

With the exception of two studies involving Prozac, the improvement in the depressive symptoms with the medication does not differ from the positive response from the placebo group. The common finding is a 69% improvement in mood with the medication and 65% improvement in mood with placebo. The issue then became, if the medication is not any more effective than the placebo, why expose individuals to twice the risk of suicidal thoughts? Now the process gets more complicated!

**Those of us working with depressed patients on a daily basis know these medications work. Why don't the studies support what we know as clinicians?**

One possibility is the design of the studies. Children and adolescents are highly suggestible and readily affected by treatment interventions. They also have difficulty reporting their symptoms. How many parents

Continued on page 3

## Shared stories bring hope...empower families

One goal of this newsletter is to spread information and support—and also encourage others to tell their own personal stories. Please consider reaching out to others this way. You may remain anonymous, as in the following excerpt from a mother whose child was hospitalized with bipolar disorder and is now a successful college student:

"Recognize that a child in crisis means a family is in crisis. Seek and accept all the help you can get for your child, yourself, and your family. Getting an accurate diagnosis is the first step to healing and recovery. Let your child know that he or she has a treatable, physiological disease. Be kind to yourself and do not blame yourself or others. Celebrate your child's strengths and know there is hope and there is help."

Paul Raeburn, parent and author, shares his family's poignant account in [Acquainted with Night](#):

"Until we are willing to talk about our

children and our families publicly, America's tragic failure to care for its mentally ill children will continue. It is up to us; no one else can fight for them as fiercely as we can."

From a "twenty something" college graduate successfully managing a generalized anxiety disorder:

"Healing takes place when we build awareness, when we acknowledge the disorder, when we accept the diagnosis and embrace therapy (sessions and medication). I've come to see an accurate diagnosis as a gift. Healing takes place when we share our story. Only then may we come to peace."

Help us reach out to others. Patients, families, educators, medical professionals, and friends can participate.

Contact Changing Minds by e-mailing JulieR.Webster@cchmc.org to share your story.

### In this issue:

Antidepressants  
Spotlight on ADHD  
The Power of One  
Shared Stories  
Special Needs  
Resource Directory  
Web Links

"This newsletter is produced and edited exclusively by parent volunteers. Nothing contained in this newsletter should be used as a substitute for a professional's diagnosis, advice, or treatment. Reading this newsletter constitutes an agreement to hold harmless all volunteers and contributors for anything contained in this newsletter."



## ADHD diagnosis is not a simple process

By Dulcey Griffith

Attention Deficit-Hyperactivity Disorder (ADHD) has gotten a lot of press over the years, but for all its “fame,” it is still a complicated diagnosis and different from its sister disorder ADD.

ADHD is marked by three main characteristics. The first, impulsivity, is most often demonstrated when the child does things without thinking: answering before the child thinks, hitting another child, running out in the street. The second is the inability to pay attention at school and at home. Third is hyperactivity, which parents frequently describe as if “their children were driven by a motor.”

Diagnosing ADHD should be complex and thorough. Author Patricia Kennedy, in [The Hyperactive Child](#), lists six guidelines:

- At least two sources (parents, teachers and doctors) reported the child has poor attention span, poor impulse control, and poor compliance with instructions, poor self-control, and poor rule-governed behavior.
- The behavioral problems have placed the child in the top 3 percent for symptoms of ADHD as compared with other children of the same age and sex.
- The behavioral symptoms began in early childhood and before five years of age. (Teenagers, for instance, who suddenly develop symptoms of ADHD may have hormonal or environmental changes that cause attention problems, not Primary ADHD.)



- The symptoms are on-going and occur in multiple settings.
- The child has an IQ of 70 or higher: if mentally retarded, the child must be compared with other children of similar mental age for behavioral assessment.
- The diagnosis of Primary ADHD excludes the following causes: mental retardation, deafness, blindness, gross brain damage, severe language delay, childhood psychosis, autism, cerebral palsy, and severe emotional disturbances.

Usually a child with ADHD has many of the following symptoms, which are common to people with attention problems. However, many individuals with attention problems but without ADHD have some of the same problems on this list.

- Purposeless selection of stimuli- listens to the air conditioner instead of math lesson.
- Weak resistance to distraction – easily distracted by all types of stimuli.
- Impersistence- is unable to stick with a task.
- Inefficient motor activities – or unproductive hyperactivity: on the go, but going nowhere.
- Insatiability- wants all the toys in the toy box, but when he/she has them, demands more.
- Impulsivity- acts without thinking.
- Academic failure- poor school work.

- Social failure- poor peer relations, difficulty making or keeping friends.
- Performance inconsistency- has good days and bad days. Some days he/she understands math lesson and the next day he/she will not remember how to do it.
- Attention difficulties- trouble staying on task.
- Diminished self-esteem- feels badly about self.
- Disorganization- difficulty in organizing how to do tasks.

Scanning the list of symptoms, you can see why a checklist alone is not enough to diagnose Primary ADHD. Medical intervention is needed to receive an accurate diagnosis.

**Dulcey Griffith, RN**, is a member of Psychiatry’s Parent Advisory Committee at Cincinnati Children’s. This ADHD outline came from the book [The Hyperactive Child Book](#), authors Patricia Kennedy, Leif Terdal, Ph. D., and Lydia Fusetti, M.D. This article is not to diagnosis your child, but to help you to understand what signs and symptoms to look for in an ADD/ADHD child. Please seek medical attention with your doctor if you have any question or concerns. This material is just a reference book on ADD/ADHD.



## The decision to use antidepressants is a complex one

Continued from page 1

see their child is upset, yet the child denies it? The child might not recognize or understand his or her feelings or reactions. Most of the drug trial data is based on self reporting. Analyzing this can become very difficult.

Most of the studies are funded by the pharmaceutical companies that have a financial incentive from the government. The two studies that have shown clear evidence of improvement in mood versus placebo were not funded by drug companies. It is possible that the screening and organization of the studies are different among the various agencies. Many questions remain in this area.

So, medicate or not? Depression is a serious and possibly like threatening illness. Suicide is a known risk. Failing grades, social isolation, substance abuse, and other risky behaviors are common; patients often live in general misery, including poor sleep, depressed mood, and lack of energy. An untreated major depressive episode could last 7-9 months and milder form, such as dysthymia, can last for years. Various interventions have been shown to help. Cognitive behavior therapy and a variety of individual, group, expressive, and family therapies have shown success.

So why use medicine? Medication can take effect in as little as two weeks, where some therapies will take months, require frequent visits or not be available in the local area. More severe depressions may have a biological or genetic component. Current research suggests that a combination of drugs and therapy can provide the best and most stable long term intervention to decrease the incidence of recurrent depression.

I recommend more aggressive treatment based on the impairment of the illness. If the individual is failing in school, missing class, withdrawn from family and friends, losing interest in previously enjoyable activities, becoming hopeless about the

future, and engaging in risky behaviors such as sex and drugs - then aggressive treatment is indicated. The level of the individual's distress is also an indicator. Suicidal attempts or ideations require the highest level of intervention, possibly hospitalization, in addition to medical treatment.

One does not have to have severe symptoms to benefit from medication; lower levels of depression may be stable enough to try other interventions first, but medication should be tried if symptoms do not improve.

**If your child is on medication, look for these signs:**

**More irritability**

**Restlessness**

**Withdrawn**

**Increased sleep disturbance**

**Thoughts or behaviors that suggest suicide**

**Any types of bizarre or unusual behaviors should be reported immediately to your doctor.**

**Guns and alcohol are a deadly combination - if anyone in your household is depressed, remove all of them immediately.**

**Lastly, don't stop a medication without consulting your doctor. The data is very limited and questions remain.**

All the information is based on short term studies and suicide rates since the introduction of antidepressants have decreased. If they were causing suicide, rates should be increasing. Some of the medications can cause withdrawal reactions if abruptly stopped, so please ask your doctor before making any changes.

Depression is debilitating and treatment is effective if provided in a timely manner and appropriately monitored. The antidepressants have improved the lives of many people. While they potentially have serious side effects, with appropriate diagnosis and monitoring, they can be very effective and safe.

### THE STUDY

An intensive review of 4100 children/adolescents involved in medication trials studied all data on antidepressants available for that age group. Suicidal thoughts and attempts and self harm thoughts and attempts were reviewed comparing active versus inactive medication groups. Medications studies frequently involve comparing two groups of individuals, those receiving the actual medication and those receiving a placebo, a pill with no active ingredients. No one knows who is receiving the medication, which eliminates the "placebo" effect of reporting symptoms caused by a belief that the medicine is working. It also helps to clarify whether reported side effects are actually from the medication or whether they occurred in those not receiving the "real" drug.

"You must be the change you wish to see in the world."

Mahatma Gandhi

## Changing Minds

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If you would like a copy of  
this newsletter, call or e-  
mail us!

"Our greatest glory is  
not in never falling,  
but in rising every  
time we fall." -  
Confucius

For more information please check  
these related links:

CCHMC's Psychiatry website:  
[www.cincinnatichildrens.org/svc/alpha/p/psychiatry/](http://www.cincinnatichildrens.org/svc/alpha/p/psychiatry/)

NAMI ( National Alliance for the  
Mentally Ill):  
[www.nami.org](http://www.nami.org), or [www.nami-hc.org](http://www.nami-hc.org)

Hamilton County, Ohio  
Ohio Federation for Children's Mental  
Health, In:  
[www.ohfederation.org](http://www.ohfederation.org)

Special Needs Website Directory:  
<http://www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/default.htm>

## Trust your parental instincts

A mental illness diagnosis can be devastating and overwhelming. The information available can be confusing and frightening, and access to the medical community often does not seem readily available. There are a few simple suggestions that can make a world of difference. When meeting with a physician or medical team, remembering that you are the best "expert" on your child. It helps to prepare a list of questions, and bring records of past medical evaluations, school reports, medication lists - anything that will help give the team a full understanding of your child.

Remember that their time is short - so list questions in the order of priority.

Try to be succinct. Air your concerns and give data to substantiate them.

If you are in strong disagreement, it is acceptable to challenge the treatment plan or diagnosis, as long as it is in a positive manner. Remember you are part of the team and a valuable asset. While there are always exceptions, remember that the vast majority of professionals also want the best for your child. Trust your instincts, fight for what you truly believe in, and take care of yourself and others in your family.

*Lisa Eccles is a member of the Psychiatry's Parent Advisory Committee and volunteer editor of the newsletter.*

## Special Needs Resource Directory Updates

The Special Needs Resource Directory, available on the Cincinnati Children's web site, provides access to a comprehensive set of links to local and national resources. Families and caregivers of children with specialized health care needs can quickly connect to a variety of worldwide web resources for information covering more than 35 subjects, including:

- Advocacy
- Day care and respite
- Disability-specific web resources
- Estate and future planning
- Mental health
- Financial assistance
- Recreation opportunities
- Residential placement
- Support groups

Reaching the Special Needs Resource Directory is easy. From your computer, search under [www.cincinnatichildrens.org/special-needs](http://www.cincinnatichildrens.org/special-needs). You can then click on **Mental Health** to easily connect to websites covering local mental health services, advocacy and support groups, case management, information, substance abuse, suicide, and mental health screening tools. The directory is updated continuously with expanded information about each topic, informative and easy-to-use links, and growing connections to key web sites.

Created by the Center for Infants and Children with Special Needs at Cincinnati Children's, the resource directory is designed to be a reference for all parents and medical professionals. Access to local Ohio, Kentucky and Indiana resources as well as national web sites, is just a click away. For more information, please call Ava Fried, Marketing and Communications, Cincinnati Children's Hospital Medical Center, 636-1970 or email

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