

*United as Parents,
All Our Children Succeed*

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Missoula, October 26

Brought to you by the Missoula Associate Board in conjunction with the Missoula Children's Theater

— For more information, contact
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PLUK Begins 20th Year

In August PLUK held its first annual Corporate Softball Tournament in Billings. Nine companies attended the event, participating in a fun tournament that served as a fund-raising benefit for PLUK.

Teams came from Senator Max Baucus' Office staff, Exxon Mobil refinery, Farmers' Insurance Company, Billing Gazette, KTVQ2 TV, KULR8 TV, Montana-Dakota Utilities, US Bank and the Yellowstone County Attorney's Office. Exxon defeated Montana-Dakota Utilities in the championship game for the tournament title. We appreciate the companies who participated and the volunteers who helped make it a success. Special thanks to Scott Harris, PLUK Associate Board member, for his hard work and participation. We're already working to plan next year's tournament.

Over the summer, PLUK has welcomed three new members to its governing board: Wayne Erlenbush, Vice President of US Bank in Billings; Jeff Randel, Chief Financial Officer and Community Resources Director at ConocoPhillips Refinery; and Sarah Blackburn, Social Worker at Deaconess Billings Clinic, Pediatrics. The board oversees the program's operation and planning. We are very lucky to have such outstanding community-minded individuals give of their time and experience to assist with the growth and development of the organization. We've also added two new staff members, Rebecca Adams in Bozeman & Todd Hoar in Butte. They have been longtime friends of the organization and now offer their knowledge and experience to assist families in their regions.

In early September we held our fall staff

training. The Founder's Day Celebration on September 8 recognized the work of PLUK over the last 20 years. We were fortunate to have Julie Beckett participate as the keynote speaker. Julie is one of the national policy directors for Family Voices and the mother of Katie Beckett. Julie's story about Katie, President Reagan, and how an individual can indeed have the impact to effect change in a massive government system is inspiring. She applauded the work that PLUK has done over these last 20 years. We appreciate Julie and her dedication and willingness to help others. We also recognized several individuals for their lifetime of work for the benefit of families: Dr. Kathy Kelker, Dr. Gail Gray, Julie Beckett, Gary Pagnotta and KTVQ2 television in Billings. PLUK thanks you for your support of children with special needs.

Many of the children of families that PLUK has supported over the last 20 years are now successful adults. Some work on our staff. They are a testament to the success of the system of supports within our early childhood and education systems. Imagine the changes in the next 20 years as we continue to work together for the benefit of all our children. ❖

— Dennis Moore, Executive Director

*"Peace cannot be achieved through violence,
but only attained through understanding."*

— Albert Einstein

What is PLUK?

Parents, Let's Unite for Kids is a statewide parent organization that provides support, resources, and training to families who have children with special needs and the professionals who work with them. Covering topics ranging from infancy to adulthood, PLUK offers various statewide resources and individual support in homes, schools and medical facilities.

ONLINE INFORMATION
<http://www.pluk.org>
 Visit our Web site for the most current information.
 View publications and trainings.
 Search the archives and library.

Who Should Call?

- ♥ Parents of children with special needs, chronic illnesses, or disabilities.
- ♥ Parents of children with emotional or behavioral problems.
- ♥ Parents needing encouragement & moral support from other parents.
- ♥ Family members & friends of persons with special needs.
- ♥ Individuals with disabilities or chronic illnesses.
- ♥ Professionals in medical, educational or human service fields.

When is PLUK Open?

The PLUK central office in downtown Billings is open 8:00 a.m. to 5:00 p.m., Monday through Friday. After hours or when unavailable, our voice mail records incoming calls and we respond on the next business day or sooner.

Is There a Cost for PLUK Services?

All PLUK's services are *free* to individuals with disabilities and their families.

What Services Does PLUK Offer?

Information

- ♥ State-of-the-art special needs library (materials mailed to anywhere in Montana at no charge)
- ♥ Training in parenting, communication, advocacy skills, and more
- ♥ An information-filled newsletter
- ♥ Computer lab with adaptations for people with special needs
- ♥ Referral to medical, educational or human services
- ♥ Assistance in seeking financial resources

Support

- ♥ Individual assistance and emotional support
- ♥ Trained advocates
- ♥ Mediation and conflict resolution
- ♥ Referrals to parent support groups
- ♥ Parent-to-parent contacts

How Can I Get in Touch?

Stop in at the main office
516 N 32nd St.
Billings Montana 59101-6003

Call us at 406.255.0540 or
800.222.PLUK [7585] (toll free)

Send us a fax at 406.255.0523

Check in with us on the Internet
E-mail: plukinfo@pluk.org
Web site: <http://www.pluk.org>

Where is PLUK?

PLUK's services are available to individuals and families throughout Montana. The main office, library, and computer lab are located at 516 North 32nd Street in Billings. Satellite offices are located around the state. (Please see page 15.)

PLUK News

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Accessibility: PLUK News is available in alternative formats by request. Today, we endeavor to be conscious of the need for making all information accessible as we are aware of physical accessibility issues in our community. For design guidelines visit <http://ncam.wgbh.org/cdrom/guideline>.

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Interview with the Experts

How Drugs Affect the Brain

Dr. Bertha Madras, a professor of psychobiology at Harvard Medical School, is one of the world's leading researchers on certain aspects of the way the brain works. She was in Billings in early May 2004, presenting at a conference on drug and alcohol abuse. The Harvard Web site introducing staff and faculty says that Dr. Madras' "work on drug addiction has led her to take up what she calls a 'crusade' to warn the public about the devastating impact of drugs on the brain." One of her major research interests is exploring how drugs work in the brain, and in the course of her research she discovered something important about how the brains of children who have ADHD differ from the brains of children who do not have this condition.

It turns out that one of the striking differences between the brains of people who have ADHD versus the brains of those who do not have ADHD is in the way their brains handle an important neurotransmitter called "dopamine."

One of the interesting discoveries Dr. Madras made is a compound called Altoprane™, a substance that attaches itself very specifically to the dopamine transporter in the brain, allowing the area where it attaches in the brain to be studied in a living person. A little bit of fast-decaying radioactive substance is attached to the Altoprane™ to allow radiologists to actually photograph and measure the differences in brains, using a technique called single photon emission computed tomography (SPECT) imaging. A pilot study showed that individuals having ADHD had dopamine transporter density two to four times normal. Altoprane™ is of interest because it might lead to the first commercially available, physical test for ADHD.

On May 8, Dr. Madras gave an interview to Mark Taylor & Rosanna Buehl,

for *PLUK News*. The following is an edited summary.

Is ADHD Real? How do We Know?

Taylor: In the course of my work as a school psychologist I talk to a lot of parents about ADHD. It is not uncommon for parents to object, saying that they simply do not believe in ADHD. My question is, do we know that ADHD exists, or am I really just expressing a belief on my part when I talk about ADHD?

Madras: Yes, ADHD does exist. I think that the first thing to say is that there are a number of studies that indicate that ADHD is to a large extent a genetic disorder. The genetics account for more than 70% of the disease.

Taylor: How is that compared to other conditions we know about?

Madras: It's very high. In fact, it is one of the highest. It is higher than for schizophrenia. It is higher than many other disorders that are associated with the brain. The patterns of behavior have been documented since the turn of the 20th century. They were first described

by an English physician in London, I believe around 1902, and it was controversial then. From that point on, until the 1930s, a number of children who had ADHD were isolated from other children because their behavior was so disruptive.

Then someone tested amphetamine on them in the mid-1930s and found that low doses of amphetamine have a remarkably positive effect on the disorder: the children calmed down, their grades improved in school, and they were far, far better off in terms of their long-term outlook than untreated children. From that point on, it came to enter the mainstream of thinking that ADHD is, in fact, a brain-based disorder, because it is treatable with drugs.

Another line of evidence showing that ADHD is a biological disorder is that there are a number of studies now that show structural differences in the brains of children with ADHD when their brains are scanned.

Taylor: So at least in the laboratory you can see an actual difference in brains on medical imaging?

Madras: You can actually see it. You can see it with anatomical MRI [magnetic resonance imaging], and you may be able to see it with fMRI [functional magnetic resonance imaging] as well. There are several brain areas that are different, including: the cerebellum, the striatum, and the prefrontal cortex. There is a mounting body of evidence.

Taylor: Are we soon going to be able to do a simple medical scan and...

Madras: No, and the reason we are not going to be able to is that there is still overlap between normals and those having ADHD. When we did our first study, we were astonished that there wasn't any overlap between these two groups. It turned out that we just were lucky. It is possible that none of our subjects used tobacco, but nobody even asked. We didn't even dream that

smoking could make a difference. We didn't know. So in the first study we had no overlap, but now, more recently, we have overlap. To say "yes" or "no" based on the kind of medical scanning we are doing is not going to work out, but it is going to help.

Taylor: But in children, you don't have as many smokers.

Madras: Precisely. But being able to do imaging in children is a challenge.

Taylor: Of course; Altoprane™ uses radiation. That makes it difficult when you want to study children.

Madras: That is right. Hopefully, we can circumvent it. There are dopamine transporters in other areas and my dream is to be able to find them floating around in some blood cell so we can measure them there without having to expose anyone to radioactivity.

The Koreans have done similar imaging studies with a completely different probe. They used one of their own, and they did it in children. It is easier to get this sort of approval in Korea. They found a 50% increase in the dopamine transporter in children who have ADHD. On the other hand, one group in the US, at Yale, did not find any difference, but in the US it is only possible to do this kind of study in adults. I don't know if the Yale study included smokers. We have a long way to go.

Until the story is complete, I always say let's have a multi-centered trial. This will be years and years of study, where we enlist many centers. We need to do the study in as many places as possible and hope that everyone gets the same data. If we don't get consistent results we know we have to rethink the whole thing.

Taylor: When I was looking at your success in imaging ADHD, I immediately started reflecting that the controversy over dyslexia, which was huge until Sally Shaywitz¹ came along in 1998 with all of her neuroimaging work at Yale. The publication of her study basically



Bertha Madras of Harvard Medical School speaks with Mark Taylor

settled this question. Suddenly, I could tell people that dyslexia is something we can see, in the same way that we can see the bones in our bodies with x-ray. I am thinking that with your work and that of Nora Volkow at Brookhaven, now we can see ADHD. We can see it with medical imaging.

Madras: We are beginning to see it. Yes. Absolutely. However, there are two confounding factors that I think we should consider.

First has to do with the environment in which a child is raised. For example, children who come from what is called "lower socioeconomic status families" show the symptoms more strongly. That really could be an environmental issue. If these children are in a state of anxiety at home because their parents' lives are in chaos because they don't know how they will pay the next rent, that could make the behavior in the children worse. I think it is important to recognize that environmental factors can shape and mold what emerges from the genetic material that the child inherits.

Second, the genetics are very, very solid now, but there are at least six or seven genes implicated. The dopamine

transporter is only one, and there are others. There are several kinds of dopamine receptors, there is the serotonin transporter, and others that have a very strong association with ADHD.

Buehl: I think it is comforting to parents to be able to say, "We don't have the technology and the science yet to make this kind of physical diagnosis, but we can see ADHD on imaging in the laboratory."

Madras: We are beginning to see. It should be pointed out that there are a number of disorders of the brain where a pure biological test has not been developed, but functionally the behavior of these people is such that it makes it difficult for them to have smooth and reasonable lives. An example of that is schizophrenia. Another example is depression. There isn't a solid biological test for either of these very serious disorders. Yet when a person is depressed they are very unhappy; their surrounding family, their work, everything suffers.

How Does ADHD Affect Learning?

Taylor: I am wondering about the effect on learning. It seems to me, based on what we know about the biology of

learning, that when you are not paying attention you are not learning. Because the brain is so well defended against learning everything that ever happens around you, you only learn the things that you pay attention to.

Understanding Neurotransmitters

Neurons (brain cells) have to communicate with one another without touching. They do this by releasing chemicals into the gap between the cells (the gap is called the "synapse"). Chemicals released from one cell are picked up by the next cell, causing a signal to fire through the receiving neuron.

Until they are released into the synapse, the chemical molecules are stored in the first cell in little containers called "vesicles." When they are released, they float across the synapse until they reach sites on the second cell called "receptors."

There are many different kinds of chemicals that serve to transmit signals across the synapses of the neurons. These are called "neurotransmitters," because they transmit signals from one neuron to another. The receptors for each kind of neurotransmitter are specifically shaped to fit that kind of molecule and no other. They fit like a lock and key, each specific kind of neurotransmitter fitting only into one kind of lock (receptor).

Once the signal is triggered in the receiving neuron, the neurotransmitter molecules are released from the receiving cell and float back into the synapse. Because it is difficult for the body to manufacture neurotransmitters, they are vacuumed up again by the sending cell so that they can be re-used. Within about two seconds, the synapse is cleared of the neurotransmitter molecules. The part of the neuron that sucks up the neurotransmitter molecules is called a "transporter."

Of the many different kinds of neurotransmitters, one called "dopamine" is known to be very important to the understanding of ADHD.

Understanding the dopamine system in the brain turns out to be a key to understanding why stimulant medications are often so helpful in treating people who have ADHD.

One of the functions of the dopamine system is to signal when it is important to pay attention. The signals transmitted through a neuron when dopamine is released into the synapse say "this is important," and they make it pleasurable to pay attention. Without enough dopamine flowing into the neural circuits, information becomes garbled and events that would be interesting enough to most people seem "boring."

It turns out that people who have ADHD have more of the "dopamine transporters" than normal. For them, dopamine is released normally from one cell, but before it can find its target receptors on the next cell, it is vacuumed up by the first cell's dopamine transporters. Too little dopamine gets across the synapse, so the receiving cell does not fire strongly enough, and attention is not engaged.

Stimulant medications, such as Ritalin, work because they "gum up" some of the dopamine transporters, making them less effective vacuums. As a result, when dopamine is released into a synapse it is not immediately sucked up, but stays in the synapse long enough to find its targets. For a people with ADHD this is very desirable because for them it normalizes the dopamine system.

Madras: Yes. There are over 160 studies in children with ADHD, comparing treated children with untreated children, and within those studies I don't even think there is even one negative finding. In fact, they show unequivocally that children with ADHD improve in terms of school, they improve behaviorally, their behavior at home improves, and their grades go up, when they are treated. Being able to pay attention and not be distracted does help them learn more, and it improves their future potential. What Ritalin and amphetamine do is enable a person to focus and pay attention to the task at hand. That is very clear.

I might add, one of the biggest problems in drugs in universities is diversion of Ritalin to students who do not have ADHD, to help them study. It enhances focus. For this reason people who are prescribed drugs for ADHD are very popular on campus because they are asked to sell their pills to people without the diagnosis. There are even a lot of students who are coming into health clinics at universities saying they have ADHD, in order to have the physician at the clinic prescribe Ritalin so that they can study and get better grades. These are young people who do not have ADHD who are pursuing the drugs, not to get high, not to enhance their mood, but to be able to study. I think that college students are not stupid. So what I am saying, in effect, is that the diagnosis and the treatment of ADHD has a good, solid, scientific base.

Aren't There Dangers Associated with the Use of Medication?

Taylor: Are their dangers that concern you with the use of drugs to treat ADHD?

Madras: Well, the drugs can have a range of side-effects that are unacceptable. Some children taking these drugs will have a hard time sleeping.

Some children will fail to gain weight normally. Some children will get upset stomachs from the drug they are taking. Some get anxious. On the other hand, some children don't even respond to these drugs at all. With regard to side-effects, one has to be alert to them. There is another drug that just came out, called atomoxetine, which appears to have fewer of these kinds of side-effects, but may have others.

In terms of the long-range effects of prescribing drugs of this nature to children, amphetamine has been around since the 1930s and Ritalin since the 1960s, and there have been numerous studies to evaluate whether or not there are some devastating effects on brain function after years of being exposed to them. The data do not indicate that there are long-term negative effects. There still are a lot of questions unanswered, but it is important to point out that the doses that are used to treat ADHD are far lower than the doses that people use illicitly in order to achieve euphoria.

Taylor: And, of course, people take these prescription drugs by mouth.

Madras: Yes, and that's a huge difference between the medically guided use of these drugs for treatment of ADHD and illicit use of other stimulants. For treatment of ADHD, people take these drugs by mouth. The amount that gets into the brain, that occupies targets, is much, much less than it would be by some other route of administration. For any drug, the toxicity as well as the psychological effects are affected by: dose, purity, route of administration. Those are the big factors.

Buehl: You mentioned that there is a certain percentage of children who don't respond to the currently used prescriptions at all. What does science tell us about those kids?

Madras: Oh, that's a wonderful question. We have been working on a

receptor that has just been cloned by another group, and I had a potential "eureka moment," because I said, "This receptor is very strange: it responds to amphetamine. No one had every thought that amphetamine has a receptor as a target. Everyone assumes its target is transporters, which is a very different class of protein. So, it became a "eureka moment" when I looked in the literature and said, "What does this receptor potentially do?" It turns out that it is activated by a compound in the body called phenethylamine, which is a trace amine. And then I looked in the literature with ADHD and found that children with ADHD have 50% lower levels of phenethylamine in their urine. There are three studies that have been done now that are solid. And if you give them anti-hyperactivity drugs, the levels go back to normal.

Don't write this, because this is a complete and total unpublished theory. I am writing a review of it and I don't want anybody to know this until it comes out. Nobody knows, not even the ADHD community — because it would be gone in a minute. This doesn't quite address your question, but I am beginning to think that we have to look very carefully at this whole system, that it could be that there is a sub-population that has problems with this receptor. And that is very interesting. It could be a whole new way to look at ADHD.²

Now, does the dopamine trans-

porter play a role? Well, it is so interesting, because the first question I asked was: if methylphenidate or amphetamine hits the transporter, how in the world can this fit into this new receptor? And it turns out that phenethylamine, like dopamine — this is what we just finished doing in the lab, again unpublished, off the record — uses the dopamine transporter to march into the cell. So that if you block it with Ritalin or with amphetamine, you are doing to phenethylamine just what you are doing to dopamine.

Taylor: And it is leaving, in effect, more of these chemicals in the synapse, so that they are more available for the target receptor.

Madras: Including phenethylamine. Now, you must not breathe a word, because it may fit or it may all fall apart. But right now, I am beginning to... I am almost in a... I am really... science is euphoric. I am in a state of euphoria, just waiting for the final numbers so that we can write this up!

Controversy

The diagnosis and treatment of ADHD has been the subject of extreme controversy. In part this is due to the concerns anyone would have about long-term use of any medication, but is primarily the result of a concerted effort on the part of a few highly committed groups to paint a negative picture of their effects.

Of these groups, the Citizen's Commission on Human Rights, wholly funded by the International Association of Scientologists, has spent many years and a great deal of money getting out a message that ADHD and dyslexia "and other frequently diagnosed learning 'disorders' are merely a for-profit hoax." They claim that there is no scientific evidence to support the idea that these sorts of disorder even exist. Their literature claims that "ADHD was invented, in committee, at the American Psychiatric Association in 1980." With regard to dyslexia, they warn that "what parents are not told is that more than 60 years of research has failed to confirm that a defect of any sort exists in the brain of a child who is labeled dyslexic."

Madras, continued from page 6

Buehl: What would you say to a parent who is reluctant to pursue medication for ADHD because there is a strong history of substance abuse in the family?

Madras: That's an excellent question. Tim Willens and Joe Biederman, together with their colleagues have published several studies showing first of all that children untreated, unmedicated for ADHD, are more likely to use cocaine and certain other drugs than treated children. In fact, the use of illegal drugs in treated children with ADHD goes down compared to the untreated. Use of prescription medication for ADHD not only does not promote illicit drug use, it has the reverse effect. It makes illicit drug use less likely.

It is very important to distinguish between children who have ADHD that's a bona-fide disorder from children who are very troubled because of their home environment and who are acting out at school. Also, a child might be acting out because of other psychiatric problems, such as oppositional defiant disorder. There is a large shopping-list of behavioral problems that are not ADHD. I think that the diagnosis of ADHD has to be made by individuals who are very well educated with regard to the range of behaviors that children can present, and who have a good understanding of what types of approaches could be used to help these children.

Buehl: How do you answer a mother who is concerned about accepting treatment for her child's ADHD?

Madras: If I were to deal directly with the issue, without worrying so much about the science, I would ask her, "How is your child doing?, Could he be doing better?, Why isn't

he doing better?" I would say, "We call this ADHD, and there are things we can do to help."

In terms of ADHD, when you think of it, the most important factor in convincing a parent that there is an issue is that functionally the child is in trouble. He is probably not performing up to his intelligence in school, he is disruptive in class, he is disruptive at home. This is a problem that has to be dealt with, because if it is not dealt with, children who are bright and talented and who have potential may be lost because they are not being recognized or treated for this specific issue.

I am very much an advocate for the diagnosis, I must say, because I think that behaviors that disrupt the lives of individuals require intervention. If a child's life is disrupted, if their grades are not good, if they are failing in school, if they are not able to develop reasonable social interactions in school, if they are considered highly disruptive, and if they are working under their potential, these are functional, operational definitions that there is an important issue here that must be addressed. ❖

Endnotes

- ¹ Shaywitz, S.E. *et al.* (March 1998) Functional disruption in the organization of the brain for reading in dyslexia. *Proceedings of the National Academy of Sciences USA*. Vol. 95, pp. 2636-2641.
- ² Three months after our interview, Dr. Madras announced this hypothesis to the world at a conference in Denmark in August 2004. (Benzon Symposium No. 51. Neurotransmitter Transporters: Basal Function and Drug Targets.) The title of her paper was "Genetic variation and transporter pharmacology." <http://www.benzon-symposia.dk/sites/abstract51.htm>

Founder's Day Celebration



Above: Katie Bonnell and Mom

Below: Brittany Swedelius and Mom



Below: Festivities, speeches, awards, food, and friendship mark the annual celebration



Ask PLUK • Ask PLUK • Ask PLUK • Ask PLUK

Answers to the questions that are being asked by families, educators and others in Montana appear below.

You can send your questions to "Ask PLUK" by mailing a note to Ask PLUK, 516 N 32nd St., Billings, MT 59101-6003 or sending E-mail to plukinfo@pluk.org. Please make your questions suitable for public review by keeping the topics general rather than pertaining to a specific person or school.

Q I read recently about a family who was struggling to restrain their son's tendency to wander. I wanted to recommend a boundary program and thought that you might explain the principles behind this strategy so that other families could consider it.

A Thank you for the "heads up" so to speak. Yes, boundary programs are a good option for many families with similar concerns about child safety and basic behavior rules. A phone call to Family Outreach Inc. in Helena reveals that the nature of most boundary building programs is based first on positive reinforcement, then on ease of use for parents and providers, and finally on highly transferable cues.

Boundary building starts by surrounding a child within a simple, obvious, barrier; a good example of this is a refrigerator box, kiddie pool, or other material that can be easily picked up and moved. Then parents can use positive reinforcement to reward the child for staying within the boundaries of the barrier. The child will be rewarded for spending gradually longer periods of time within the boundary. Once the child recognizes the area inside the boundary as an appropriate, rewarding place to spend time, the barriers can be moved to various areas around the house and the reinforcement continues. When the obvious barriers can be moved with ease, and the child responds to the boundary in any part of the house, the refrigerator box or other physical barrier can be changed to a less obstructive form like foam "noodle" pool floats or hula-hoops. Using these "soft" barriers, parents can gradually began to move the boundaries again, this time progressively fading the prompts. Eventually, parents may be able to mark boundary barriers with tape on the floor, then perhaps, only with a piece of tape.

As readers can probably tell, boundary programs are time-intensive, and are not "quick fixes," but they can be used with children of various ages, and the positive reinforcements, like the physical barriers, are highly customizable. As with any form of behavior modification, training and support from a professional is essential. The key to the success of the boundary program is to establish for the child a relationship between safe, fun places, and the area marked inside the barrier. ❖

Q Do parents of disabled children have any rights in the workplace? My shift has been changed - this is wreaking havoc on them.

A Yes. Read Employment Law Protections for Parents of Disabled and Ill Children by attorney Loring Spolter. The Family and Medical Leave Act (FMLA) provides important job protections to parents who take time off from work to be with children receiving medical and psychiatric care or are recuperating from serious health concerns. <http://www.wrightslaw.com/advoc/articles/fmla.protect.spolter.htm> ❖

Casey's Story

By Bobbie Thurston

Born at twenty-three weeks gestation, no one thought Casey Staudinger would survive. However, he showed everyone that he was not only a survivor, but also a treasured miracle. Despite being born with cerebral palsy, myoclonic seizures and a host of health problems, he has managed not only to keep a smile on his face but also to enrich the lives others around him. Now eight years old, Casey attends Highland School in Billings and is an inspirational force to his teachers and classmates. His mother, April, admits that one of his greatest assets is his ability to connect socially with others. "Even though he is not able to speak, he works hard to make sure to participate and be part of the class. He is quite popular among his peers. They always want to sit next to him." Besides being a social butterfly, Casey possesses other qualities that shine through his personality. Casey is very kind and displays gentleness to all individuals in his life—especially his younger brother, Caleb. "When Casey interacts with his brother, he is very gentle. He works hard to make sure that he does not make any sudden movements that scare or hurt his brother. He approaches him with such care. It is very touching." Besides going to school Casey enjoys spending time with family and taking an annual trip to Rollag, Minnesota, with his dad to participate in the annual Steam Thresher's Reunion. No one knows what the future holds for Casey, but everyone who knows him knows that whatever he does will be inspiring and that he will be able to show the world, once again, that miracles do happen.

April's ability to advocate for Casey was evident during his long hospitalization at Saint Vincent Health care. She established an early rapport with the PLUK family support consultant who routinely meets with families in the Intensive Care Nursery. According to Molly Mills, a PLUK family support consultant, April addressed the challenges and concerns in a very proactive manner. She learned about early intervention services and accessed those services even before Casey was discharged from the NICU. It is sometimes difficult for parents to visualize how early learning services can benefit a child who is currently experiencing a medical crisis. April and her husband maintain an appreciation for



the benefits of educational resources as well as a firm commitment to helping Casey using any means available. April has continued to access services from PLUK. She continues to benefit from training opportunities and support. Many hours have simply been spent talking to the family support consultant and acknowledging the grieving process that is a normal part of raising a child with complicated needs. Addressing the emotional aspect of this experience has helped her focus more easily on the practical, financial, medical, and educational issues for Casey and the rest of her family.

Here is some advice from April for

parents who have experienced similar situations:

- **Be Patient:** Being a parent of a child with disability takes patience. Be aware that sometimes your life will be like an emotional roller coaster, you will experience high and lows, but know in your heart, you will survive.
- **Be Your Child's Best Advocate:** Educate yourself about your child's diagnosis. Get Early Intervention assistance. Stay involved with your child's education. Be aware of your child's needs.
- **Learn to Pick Your Battles:** When working with schools and other agencies, prioritize what is most important and what is least important. Be willing to compromise and establish a good working relationship with your child's support team.
- **Treat Your Child Like You Would Any Other Child:** Just because your child has disability does not mean you have to treat your son or daughter differently. Talk to him or her the same way. Do similar activities. Let your child thrive and grow.
- **Build Yourself a Strong Support System:** Find others within your family or community on whom you can lean for support and encouragement.
- **Continue to Educate Yourself:** As your child grows and changes, so do the medical and educational needs.
- **Become an Active Voice** in Your Community to Support Individuals with Disabilities.

Over the years, April has experienced great frustrations, but even greater success when working with the schools and medical community on Casey's behalf. She has con-

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Reports from Parents • Reports from Parents

PLUK provides grants for parents to attend trainings. In order to share the information gained we ask grantees to write a report on the information presented so that others may benefit from it..

Workshop: Let's Make It Functional

By April Staudinger

On August 12th and 13th I attended a workshop offered by OPI's Deaf-Blind Project titled, "Let's Make It Functional!! Strategies For Teaching Self-Help And Community Living Skills to Children and Young Adults with Deaf-Blindness: Developing Functional and Quality IEPs and IFSPs." Terry Rafalowski Welch, a national consultant in deaf-blindness and multiple disabilities, was the presenter.

While the focus of the workshop was strategies for teaching functional skills to children who are deaf-blind by writing functional IEPs and IFSPs, these strategies apply to ALL children with disabilities.

Terry broke down the general instructional guidelines into 5 areas:

Sensory

- ◆ Conduct functional sensory assessments.
- ◆ Support the use of available senses.
- ◆ Recognize the importance of tactile info and input.

Temporal (time)

- ◆ Accommodate for additional time.
- ◆ Be organized and consistent.
- ◆ Provide info that aids anticipation and clearly communicates "what's next."

Physical

- ◆ Attend carefully to positioning.
- ◆ Reinforce self/body as point of reference.
- ◆ Recognize communication as a sensorimotor experience.

Communication

- ◆ Address both receptive and expressive needs.
- ◆ Recognize that receptive and expressive options may differ.
- ◆ Consider environmental variables and skills of partners.

Comprehension

- ◆ Communicate at the clearest level and pace.
- ◆ Involve individual in the full sequence.
- ◆ Provide models... "Do with, not for."

Some questions parents can ask when prioritizing goals and objectives are:

- ◆ Is this (goal) motivating?
- ◆ Can it be taught in the natural environment?
- ◆ Does this use the lowest technology possible? (Can I use a pencil instead of a computer)
- ◆ Can it increase child's independence?
- ◆ Is it functional?

Terry gave us some great Web sites that address effective communication for children who are deaf-blind as well as children with severe and multiple disabilities.

- ◆ <http://www.tr.wou.edu/dblink> — provides great publications as well as databases
- ◆ <http://www.projectsalute.net> — SALUTE stands for Successful Adaptations for Learning to Use Touch Effectively
- ◆ <http://www.designtolearn.com> — tangible symbol system. Using tangible symbols for abstract activities.

If you have questions about any of the information covered in the workshop please feel free to e-mail me at ASTaudinger@aol.com or call me at 406.248.4708 ❖

Casey's Story, from page 9

tinued to expand her parental expertise as Casey's needs have changed and the family has grown. PLUK continues to play an important role in Casey's life by providing education information, training opportunities, as well as parental support. April also credits ECI and STEP as being extremely valuable to the well being of her family. She has become more politically active in the ongoing efforts to honor the rights of individuals with disabilities. Her involvement within the community has recently grown to include her participation

as a member of the STEP Board of Directors. It has been a goal of April's to "give back" to the very people who have been such an important part of her life.

Casey continues to provide great inspiration as well as the other joys and challenges of being a spunky eight year old child. His parents are both excited and sometimes exhausted by the demands of their two sons; but the future holds promise for the boy whose mother has chosen to lovingly advocate for him, their family, and others experiencing similar issues. ❖

Reports from Parents • Reports from Parents

Sweet Child of Mine, A Mother's Gift

By Beverly Stiller

When I was expecting my younger son to be born, I had no idea that I was in for quite an experience, one that most mothers do not have to face. My son's development was on track until his pediatrician told me at his two-year check up, "He should be saying more by now." She referred me to a Speech Pathologist. Six months later and twenty minutes into our visit, the Speech Pathologist said that there is definitely something that needs to be explored, so she referred me to a diagnostic clinic. Two months later, we wandered through the different specialists and came to the conclusion that there was definitely more to his story. It wasn't long before we were labeled somewhere on the autistic spectrum. So began our search for a more concrete diagnosis.

It was difficult for me to believe since physically he met all of his milestones and he always had such great eye contact, smiles and giggles. I reviewed his various baby pictures again and again searching for the sign, something I had missed. I couldn't see it. Maybe it wasn't there until later. It was these questions and all of the over-whelming information out there that led me to seek some answers.

I am one of those people who do better with research, reading and analyzing the information before I make a decision to pursue something further. Beyond getting some base testing done on my son, I didn't really know where to start. I went through the steps, or in some cases, hoops, at my son's first school. I filled out tons of paperwork: does your child do this or that, some or not at all,

etc. I found the diagnosis of the experts enlightening, enthralling, unbelievable, and sometimes even offensive. The way they described my son was not what I thought I was seeing. But, they were the experts and I took their information as a starting point for the needs of the school system. I was not going to let them tell me that he was all or nothing. I would just have to keep on them and make sure they were supposed to do what they are required to do. In the end, he was diagnosed with PDD-NOS and ADHD. He also has front temporal lobe seizures, which we figured out later, through his pediatric neurologist and a series of tests.

I found myself bombarded with a variety of methodologies, teaching modalities, theories, tales of what worked before, and complete cluelessness on how to help my child. After doing my own research, I discovered that every professional out there chooses favorite bits and pieces from each of the approaches and mostly experiments until she finds what works. If the professionals could do that, so could we.

Throughout the years, I continue to search, read, analyze and figure out what we need to do next. This led me to many different trainings and continued unanswered questions. Why does he have speech delays? Why does he search out different words, copy what someone says to him, or just jibber jabber away? Why does he like to jump in place so much? Why does he look at wet pavement and walk on it like it is hot coals? Why is he so lovable to some and indifferent to others? What is there to the diet ideas, the behavioral ideas,

the speech ideas, and all the other big and little things? Is there really a link to immunizations? Did I actually do something that harmed my son rather than protect him? I was, and am still, full of so many questions.

To seek answers to the many questions, I was fortunate enough this year to attend the National Autism Conference in Seattle sponsored by the Autism Society of America. Through the generosity of DEAP and PLUK plus my own savings, I was able to seek answers to my many questions. It was a tough assignment for me to leave my family, including my sweet autistic son in the hands of others just to go and talk and learn more about my son. The night I arrived, I spent considerable time scouring the program looking for sessions where I might find the answers to my many questions. Once I felt I had a game plan for the entire conference, I went to the lobby of the hotel to find a safe place to dine. There I met another woman, a mother and teacher, and we dined together across the street. We talked about our sons and what we had learned and discovered along the way. It was welcoming to find right off hand someone who knew what I was talking about. There is one thing that happens to folks with special children, we develop our own language, vocabulary and catch phrases that only other folks in the know actually understand. It was wonderful to find that shared mind in just the first few hours of my arriving.

The next few days were very busy. There were more than 1,700 people in attendance, teachers, professionals,

Continued on page 12

Reports from Parents • Reports from Parents

Sweet Child, from page 11

doctors, parents, autistic children, adolescents, and adults. It was enlightening to see some very high-functioning autistic children, and it gave me hope for my own child. It also raised more questions, as it appeared they were searching for their own answers.

Our kick-off session started with the entertainment of Charlie Adams, a world-renowned drummer, who tours with new-age keyboardist Yanni. He and his wife are parents of four children, two of whom are autistic. He was inspirational in his playing and it was rewarding to know that there are so many people out there living with the autistic world and its many complexities.

The keynote speakers included Dr. Geraldine Dawson, Dr. Brenda Smith Myles, Dr. Brian Iwata, and Dr. Liane Holliday Willey.

Dr. Dawson spoke of "Autism: Brain, Behavior, and Genetic Perspective," which honed in on the genetics of the disorder. She delivered an update on the research being done at the University of Washington by a group of committed scientists trying to understand the neurobiological bases of autism. This research focuses on brain circuitry — an area in cognitive sciences — to bring about a better understanding of which brain circuits allow an individual to interact with others and make sense of social information. The scientists are also looking into early biological and behavioral predictors of outcome. As a parent, listening to what they have discovered so far and what they hope to discover, I was excited by the prospect of the idea that there could be a early predictor test or something that will allow parents even more preparedness

in discovering their child has autism and to begin assisting them in their learning that much more quickly.

Dr. Brenda Smith Myles discussed "Redefining Academics for Adolescents with Asperger Syndrome and High-Functioning Autism." She talked about teaching the "hidden curriculum" — information most of us know without being taught — to these individuals, and identifying and teaching meaningful and positive skills that can enhance the outcomes for those on the spectrum. Although this lecture was interesting, it did not meet the needs of my child as it was geared towards Aspergers and adolescents. It was informative but it was hard not to say, "What about my child? What can you tell me to help my child? He doesn't have Aspergers; he has something more difficult to figure out, he is still a child not an adolescent. What am I supposed to do with this information?" I decided to tuck it away and not to worry about it until my son approaches adolescence.

Dr. Brian Iwata talked about "Behavior: Research and Observations." How severe behaviors, such as self-injurious behaviors, are really "learned performances that are required as a result of an individual's experience and they are maintained by some sort of reinforcement out there in the natural environment." I found Dr. Iwata's lecture fascinating to say the least. I had heard so much about behavior and how I could work with my son to deal with his "non-compliance" that I thought I had a pretty good grasp on the whole thing. This was new and enlightening. I am fortunate that my son has only had one true episode of self-injury that I am aware of. If I hadn't seen it with my own eyes as I was coming in the door, I wouldn't have believed he was

capable of biting himself the way he did. Dr. Iwata's theories allowed me to review that episode and see it in a different light. He continued his discussion towards "identifying those features of the natural environment that somehow maintain problem behavior in the hopes that we can use that information to design intervention programs." It was such a positive ending to a difficult subject that I felt a little lighter in my spirit afterwards.

The last speaker, Dr. Liane Holliday Willey, was diagnosed with Asperger's Syndrome and spoke of her journey, of the uncertainty and confusion, of not understanding her unique behaviors as a child, such as poor language skills and being overly honest — a behavior that was commonly interpreted as rude — to slowly building a strong support of family, friends, educators and doctors. Sadly, I had to miss this lecture in order to get to the airport in time to catch my flight home. It saddened me to have to miss this lecture because I hoped to see inside the head of someone who has autism. I have always wanted to know what is going on in my son's head, since it appears from the few written works out there by people on the autistic spectrum that there is so much more going on in their heads than most people give them credit for.

I went to many a small lecture and to the exhibition hall in between all these larger sessions. I didn't get all the answers to my questions, and even added to my list of questions, but it was good to see all the people out there, parents and professionals that care and want to do what is the very best for autism. Knowing that I am a part of that big picture and my son's world makes all the extra so rewarding. ❖

Between the Lines: Medicaid

By Elisabeth Mills

Nearly every adult with disabilities has faced the confusion of Medicaid; some states make the program as self-explanatory as a bureaucratic system allows, others, Montana included, struggle to maintain even the bare bones of Medicaid itself. As a long-time pragmatist, and a well-established Medicaid maniac, I have learned to approach the Medicaid system with well-armed humor and the simplest of information. Essentially, I know my name, my Social Security number, and usually my address. Trust me, it wasn't always this easy.

I learned that dentists are the fine diamonds of Montana Medicaid—rare. I had one, and came in many years later for an appointment only to be told that they had thrown away my file when I did not come in again after the first two years. If you find a dentist and the guy is not a barbarian, keep him, and come in every two years to stoke his ego or he will wilt. Earlier this year, I unearthed one of those polite “Please call for your appointment” notices from my eye doctor. I called and asked when my last appointment had been, thinking that time had accelerated somehow, and that two-year lag of enforced blindness, so characteristic of Medicaid policy, had rescinded early. “Last August.” She answered. Then I asked how much the office visit would cost (\$89 dollars). I must have sucked air suddenly because she asked me “Why?” I told her that Montana Medicaid would only pay for office visits and prescription glasses

every two years. She agreed to put me on the call list for next year and my glasses—scratched, much sat on, and once frozen are still perched haphazardly on my nose.

I discovered that the severity of my physical illness was inversely proportional to the availability of doctors willing to work for a pittance, and that if I wanted to find a doctor, or medicine, or a diagnosis, I'd better be healthy enough to wait a few months.

Nothing teaches the value of medical access like not having any and not being able to change that fact. I learned that quality care is not about costs but about caregivers — some are good, and some are bastards — don't settle for the bastards. I've met a few idiots in dentists' offices and optometrists' shops as well as clinics. Passport providers that you trust and that give a damn about you are hard to find, keep turning over the rocks, throw a few if you have to, and the best ones will emerge. The clinician I have now is a good man, overworked, underpaid and stressed—but he knows my name, he has protected me from the ignorance of other doctors, and he understands, unlike that dentist's office, that my poverty is not my choice. He accepts that

the majority of medicines he prescribes I will probably never take because the samples ran out last week and I can't afford fifteen dollars a month in prescription co-pays. He's worth waiting a few months for and he never makes me feel like I'm “on Medicaid.” I still don't like being a college-educated business owner who has no survivable income, but a good doctor has helped make this life better.

Now, I understand this isn't the ranting invective you may have expected when the words “Montana Medicaid” are combined—but in a world where the line between health care costs and affordable health insurance has twisted and knotted itself into a mess no one is prepared to fix—I am willing to swallow my pride, accept the state's poor opinion of my finances, and rejoice in the small things; a receptionist who will answer the phone, a PASSPORT to Health Guidebook to explain the convolutions of Montana Medicaid policy, and a Montana Medicaid Hotline

operator who, when asked if there was a list or a registry of Billings-area dentists who take Medicaid, replied, “No. You'll just have to go through the phone book.” Well, it's been ten years, and at least a dozen different phonebooks; I found another dentist, but he's in high demand

(the only one in the county, apparently) and won't be available again until sometime next year. His receptionist said, “Call back in September. There are a few slots left and we might be able to get you in before next summer.” ❖



From time-to-time, Elisabeth shares her insight on a topic of interest.

More Information

- ◆ Medicaid Program Information Handbook (Updated Jul. 04) <http://www.dphhs.state.mt.us/hpsd/medicaid/medrecip/pdf/medinfo.pdf>
- ◆ Medicaid Passport Handbook <http://www.dphhs.state.mt.us/hpsd/medicaid/medrecip/pdf/passporthandbook.pdf>
- ◆ Medicaid Recipient Hotline 800.362.8312



Patrick Erickson with Jack Horner, honorary board member

Memorials

In memory of **Mary Ann Story**
from Mickey & Bruce Weiss



In memory of **Beatrice Emmett**
from Mickey & Bruce Weiss



In memory of **Clara Hofman**
from Mickey & Bruce Weiss



Honorarium

In honor of **Patrick Erickson**
from anonymous



Honorary Board

Howard Boggess
Billings



Dr. Larry Campodonico
Billings



Dr. Rowena Foos
Billings



Dr. Gail Gray
Helena



Reid Hagen
Billings



William M. Holt
Lolo



John R. "Jack" Horner
Museum of the Rockies
Bozeman

Dr. Kathy Kelker
Billings



Nancy Keenan
Alexandria, Virginia
(formerly Anaconda)



John Kinna
Fairfield



Lloyd Shelhamer
Billings



Joyce Silverthorne
Pablo



Jack Tuholske
Missoula



Pat Williams
Missoula

Honor Others

Why not give a special honorarium to PLUK for that person who has everything? (Birthdays, St. Patrick's Day, ...and Mothers' Day are good opportunities to Honor someone!)

There are people in our world who virtually have everything they need and many things they don't need. Why buy another box of candy or flowers or for someone who has everything? Why not make a donation to PLUK as an Honorarium to that person? We'll send a special Honorarium Card and announce the gift made by you in their Honor. We can either mail the card to them, or send it to you to give to them personally. It's a wonderful way to Honor someone who means much to you, and to help PLUK and children at the same time. And, it will probably mean much more to them knowing that the donation will go to help PLUK help kids.

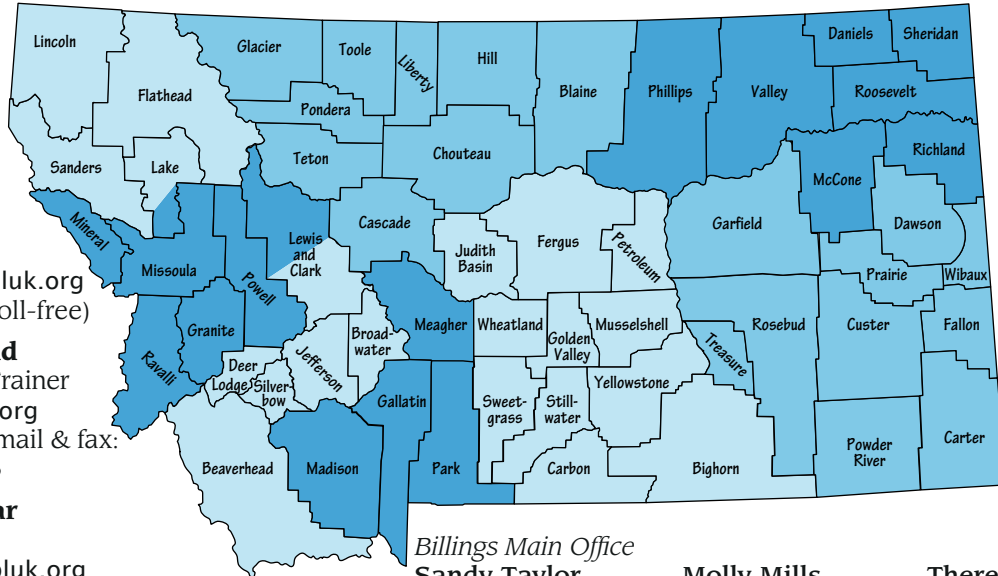
We'll list those with Honoraria in the first newsletter after the date of the Honorarium. Memorials are also available for someone who has passed away. ❖

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Parent Representatives for Part C Services

The parent representatives on the Family Support Services Advisory Council are available to hear comments from other parents about Part C services for infants and toddlers. Please contact the parent representative closest to you.

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Planning is the Key to Success

"Failing to prepare is preparing to fail." — John Wooden, basketball coach

Can you imagine educating a child with a disability without a master plan?

You do not know about the child's disability, how the disability affects the child's learning, or how the child needs to be taught. You do not know what services and supports the child needs. Is it reasonable to think you will figure this out as you go along?

If you are like many parents, you are confused about your role. What do you need to learn? How can you ensure that the school provides your child with quality, appropriate special education services?

Long-Range Planning

You need to make long-term plans for your child. You are the constant factor in your child's life. You represent your child's interests. If your child does not receive an appropriate education and master the skills necessary to be an independent, self-sufficient member of the community, you will deal with the outcome.

Your Role as Project Manager

Project managers organize, plan, monitor progress, anticipate problems, and ensure that jobs get done. On long complicated projects, project managers are essential to success.

Your child's special education is a long-term project. As the parent, you are the logical person to step into the role of special education project manager.

Learn the most common reasons why projects fail, and why you need to make plans, define goals, organize infor-

mation, and build relationships. Learn about the skills, information and attitude you need to act as your child's special education project manager.

Your Program of Self-Study

Set aside time to organize information about your child, make long-term plans, write goals with time lines, and build working relationships with school personnel. You will negotiate with the school on your child's behalf. Your goal is to get the school to provide your child with a good special education program.

You need to learn about the law, the nature of your child's disability, how your child learns, and how your child should be taught.

Learn About Your Child's Disability

Disabilities information groups and organizations are excellent sources of information for parents of children with all disabilities and handicaps. Immerse yourself in information about disabilities, handicaps, legal rights and responsibilities, tactics and strategy, and educational remediation techniques.

When you join organizations, you will receive their state and national newsletters. Information from these newsletters will put you on the cutting edge of new educational, scientific and legal developments in the field of special education. The cost of your membership will be repaid many times as you plan for your child's future.. ❖

Source <http://www.fetaweb.com/01/plan.prepare.htm>

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