FEBRUARY 2009

VOLUME 8, ISSUE 2

The Bridge

President's Message

Dear Members & Friends,

Here we are in 2009…we have heard many people say they are happy to see the end of 2008 due to the economic downturn, personal illness/loss, and gas prices not to be believed. Ever optimistic, our wishes for 2009 are: a stable economy, continued lower gas prices, good health and full employment for all our members, and a school budget and staff contract processes that can enhance learning for all children.

Education is costly, especially for children with disabilities. NOT paying for quality education for all students, however, is more costly. Anyone who remembers the time before early intervention services, can attest to this.

Taxpayers, administrators, teachers, support staff, parents, and yes, children, are all in the very difficult position this year of trying to continue to provide quality education with decreasing dollars. We ALL will be best served in the business of education if we ourselves gain knowledge of the entire budget process.

The circle of: taxpayer, employee, child and outside funding sources, (e.g. NYS reimbursement and private and public grants), is fluid. Do you recall Newton's 1st Law of Motion? (It helps to have an 8th grader in the house to consult!)

"An object at rest tends to stay at rest, and an object in motion tends to stay in motion with the same speed and in the same direction unless acted upon by an unbalanced force."

Our school district works when the education of our children is in motion. If it were to be at rest, education would be greatly hindered. Children and parents continue the motion of education by absorbing it and passing it along. If a stronger force comes along in an opposite direction to slow down or halt parts of the educational process, our children pay the price.

There is room on all sides of the upcoming taxpayer/district budget process for listening, sensitivity, flexibility, cutbacks and stretching. Honest introspection, sacrifice, commitment, respectful discussion and plain old hard work are called for by everyone. What an opportunity to teach these values to our children through our actions. All of us have the ability, responsibility and capability, with our various disabilities, to bring about this feasibility. Indeed, 2009 brings with it unique opportunities for learning!

Bonnie Goess and Cathy James

Co-Presidents

WANTED: Parents to attend MSD Board Meetings

We would like to have SEPTA representation at each Board of Education meeting. This is a great opportunity to see the happenings in the district and learn a lot. We have some volunteers but we need more.

Please check the school calendar for a Thursday evening you can attend and let us know!

- ***February 10th*** *SEPTA Meeting 7:30PM McKenna Senior Center*
- ***March 5th BOE*** *Public Session 8PM Board Room*
- ***March 10th*** *SEPTA Meeting 7:30PM McKenna Senior Center*
- ***March 19th BOE*** *Public Session 8PM Board Room*
- ***April 2nd BOE*** *Public Session 8PM Board Room*
- ***April 22nd*** *SEPTA Meeting 7:30PM McKenna Senior Center*
- ***April 23rd*** *BOE Public Session 8PM Board Room*
- ***May 12th*** *SEPTA Meeting 7:30PM McKenna Senior Center*

Membership Update!

It is with great pride that Massapequa SEPTA reports our present 2008/2009 membership is now at

522!

It is with many thanks to parents, teachers, and administrators that we have increased our membership by 160 people!

Marta Kiernan,

VP Membership

Upcoming general meetings at McKenna Senior Cen-

At our general meeting on **Tuesday, February 10th, 2009** we have invited a panel of Parents and District Parent Members to present information on what special education is, from Early Intervention services through High School; what an IEP is, how it is developed, and how to prepare for your CSE meeting. Whether you are a new comer or familiar with the process, there is always something to be learned.

On **Tuesday, March 10th, 2009**, we will welcome a speaker from BOCES, **Mary Korpi**, a vocational rehabilitation counselor, who has a wealth of information which she shares in a very comfortable manner. She will speak about preparing for transition, with tips for starting while your child is still young. Her book will be available for purchase. Look for further information in a flyer coming home with your child as the date gets closer.

We have a general meeting scheduled for **Wednesday, April 22nd, 2009**, presentation to be announced.

Parents, grandparents, friends, teachers, and administrators are all welcome to attend our meetings to learn and

Syosset SEPTA Presents Guest

Syosset SEPTA has planned two evenings with informative guest speakers. You do not need to be a member of their district to attend.

Wednesday, March 4, 2009
“The Whys and Hows of Social Stories”

Barbara Morell Baldasare, M.Ed., is the Grants Manager, Client Assistance Program Supervisor and Benefits Counselor at the Long Island Advocacy Center. She is the parent of a young man with an Autism Spectrum Disorder and often speaks on topics related to Parenting a Child with an ASD. Her presentation entitled, "***The Whys and Hows of Social Stories^{TM},"*** will introduce parents and professionals to ***Social Stories^{TM},*** a tool to help children gain proficiency in the area of socialization.

Monday, May 18, 2009
“Preparing for College with your Child with Special Needs”

Christina Bertsch is a private educational consultant and the former Director of Disability Services at Fordham University. She will be speaking on how to evaluate college support programs and services, what disability documentation is needed to be eligible for accommodations in college, the differences between special education laws K-12 vs. post-secondary institutions, pitfalls to avoid and tips for college success.

Meetings begin at 7:45 PM
at the South Woods Middle School Library
99 Pell Lane
Syosset, NY 11791
You do not need to be a member of SEPTA to attend.

From the desk of…… Tracy Von Eschen, Supervisor Secondary Special Ed. MSD

My name is Tracy Von Eschen and I am the new Supervisor for Secondary Special Education. I would like to thank everyone in the Massapequa School District for such an affectionate welcome. When I came here in September, I was received with such warmth from the parents, teachers, and all staff members. I have learned so much already and have established many wonderful relationships. I look forward to many years of working with the parents and staff in Massapequa. Working together, we can continue to create amazing opportunities for our students as we prepare them for the many endeavors that they will encounter both here at school and after.

Please contact me if you have any questions or anything you would like to discuss at 516 308-5918. Thank you again for welcoming me into your school district and allowing me to be an integral part of your child's educational career.

Thank you to all who made our fundraising successful!

The Joe Corbi fundraiser was a huge success with all 9 schools participating. The liaisons were instrumental and extremely helpful with collections and tallying their schools. Together with other members of SEPTA, they helped out during the 2 day distribution. A religion class from St Rose Of Lima helped carry all of the big orders. We raised a net profit of $8,616.50, an increase over last year. Our top selling school this year was Fairfield. Thank you to all our top sellers!

Our other successful fundraisers were the pocket calendar sale, which raised $376.00 and our Fifth Evening of Giving, which netted a $995.00 profit.

We would like to set up a committee for our fundraising next year. If you are interested in helping out, please let us know.

We have SEPTA magnets for sale for $5.00 each. Please call or email Cathy James (contact info on back page) if interested.

Lori Bonetti ~ VP of Fundraising

Access Pass for People With Disabilities

An access pass permits a resident of New York State with a permanent disability free use of parks, historic sites, and recreational facilities operated by OPRHP and the Department of Environmental Conservation. The pass holder may have free use of facilities operated by these offices, for which there is normally a charge, for example, parking, camping, greens fees and swimming. The pass is not valid at any facility within a park operated by a private concern under contract to the State.

Applications for this pass are not available online. To obtain an application or for additional information, call **(518) 474-2324** or write to:

Access Pass, NYS OPRHP
Empire State Plaza, Agency Building 1
Albany, NY 12238

Nassau County Police Athletic League has a Special Needs Unit!

The programs include: Basketball, bowling, dance, flag football, fun with fitness, horseback riding, lacrosse, recreation, shotokan karate, sports fitness, summer basketball, T-ball, track and so much more!

Visit the website http://www.ncpal.org/index.html

Or call the Massapequa Unit at 516 541-3621

Reporting in…

FROM NEW YORK STATE PTA CONVENTION

The NYS PTA Convention was held in Rochester, NY on November 7-9, 2008. Massapequa was very well represented, as was Long Island! SEPTA Board members, Bonnie Goess, Terry Yard-Healy and Suzanne Langwell attended.

This was my first time attending, and I wondered if the time away from home and family would really be worth it….leaving John with the kids and asking him to take time off from work….but, it certainly was. I brought two books…..and actually read two pages in one before bed the first night. Otherwise, there was no time to think of anything other than PTA happenings! Presidents met other presidents, SEPTA members met other SEPTA members, Long Islanders met upstate PTA members... and we all shared our concern about what is best for children.

The resolution process was a bit daunting at first, but orderly and respectful. There was a second resolution introduced the night before voting, and the night meetings and discussions were so informative. The IEP Resolution passed easily, with some revisions made by our OWN Massapequa delegation! The last minute resolution regarding scheduling for the Geometry regents in June was passed easily as well. SEPTA has had an ongoing concern about regents testing schedules, with students sometimes taking two regents in one day. With extended time needed on both hopefully...this resolution will cause the Board of Regents to examine the testing schedule with the needs of ALL students in mind.

There are many issues that need your input. I know it is time consuming, sometimes tedious or perhaps not applicable to your own issues, but I urge you to get involved on some level of PTA and begin to make a difference locally and beyond.

Respectfully submitted,

Bonnie Goess

How To Reduce Backpack Overload

by Terry Mauro

All kids struggle with overstuffed backpacks, but for children with special health, orthopedic or mobility needs, the burden can be particularly troublesome. Fortunately, there are things you can do to lighten the load.

Weigh in regularly. The About.com Pediatrics guide has devised a calculator to make sure the weight of your child's pack is appropriate to the weight of your child. Put that backpack and that kiddo on the scale and see how it balances out. If the calculator shows a problem, you know you've got to start weeding.

Get a set of textbooks for home. If your child has a disability that makes carrying loads of books inadvisable or having resources available at home for extra studying desirable, chances are you can have a second set of textbooks for home use placed in his or her IEP or 504 plan. Don't have it down in writing? It's still worth talking to your child's counselor about. If the school has spare books, they may be willing to lend them out.

Weed through papers daily. Don't let your child's folders become choked with notices, graded tests, old homework, past projects. Each little piece of paper by itself may not weigh much, but it all adds up quickly. Your child will also be more organized and more able to find papers that are actually important without all the extra clutter. A good schedule to get into is to check the pack in the morning to make sure everything's there that's supposed to be, and every afternoon to see what's new.

Check every pocket and pouch. You'd be surprised how much junk a child's backpack can accumulate. Search every inch of it and remove toys, broken crayons, extra pencils, lunchroom giveaways, behavior prizes, nice looking rocks -whatever your child puts in has gotta come out. Since you're child is likely to forget it as soon as it's stowed away, it's your job to empty out.

Beware of wheeled backpacks. They may be better on nice flat surfaces, but how many of those does your child actually encounter? If she's dragging it over bumpy sidewalks, hauling it up the school's front steps, shouldering it as she climbs to her class on the second floor, the extra weight of that rolling frame is probably not worth the coolness of the wheels.

Be the position police. Backpacks should go over both shoulders and rest squarely along the middle back. Check strap positions regularly and adopt a zero tolerance policy concerning slinging the thing over one shoulder, even if that *is* how the cool kids do it. If your child's pack is too big, or hangs too low, or has straps with insufficient padding, it may be time for a new one.

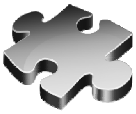
Set a good example. Just how much *does* that purse you tote around weigh, hmmm? How overstuffed *is* that briefcase? Searing back pain in parents isn't all that good for children with special needs, either.

Six New Autism Insurance Reform Bills Introduced

Kansas "Kate's Law” (Senate Bill 12), Massachusetts House Bill 0067_001,
Missouri Senate Bill 167, Mississippi House Bill 720, Utah “Clay’s Law” (Senate Bill 43) and
Washington "Shayan's Law" (House Bill 1210, Senate Bill 5203)

have all been kicked off at the 2009 legislative sessions with the introduction of autism insurance reform bills, joining New Jersey, Michigan and Virginia, which currently have active bills making their way through their respective state legislatures. All nine bills are supported and endorsed by Autism Speaks, and require private insurance companies to provide coverage of medically necessary, evidence-based autism therapies, such as Applied Behavior Analysis (ABA). Each bill has been referred to a committee and is awaiting a hearing. For more information and to take action on these bills by following the links provided at the site, please visit www.autismspeaks.org links

Obama Administration Publishes Autism Agenda on Whitehouse.gov



The newly re-launched White House website prominently features autism as part of the Disabilities agenda, where it is the only disorder specifically cited. The agenda published on the site complements President Barack Obama's presidential campaign statement on autism spectrum disorders (ASD).

In that statement, President Obama pledged to seek to increase federal ASD funding for research, treatment, screenings, public awareness, and support services to $1 billion annually by the end of his first term in office. Additionally, President Obama committed to bringing autism insurance reform to the entire nation saying his administration "will mandate insurance coverage of autism treatment and will also continue to work with parents, physicians, providers, researchers, and schools to create opportunities and effective solutions for people with ASD." President Obama has drafted comprehensive autism legislation, including a section addressing broad based federal autism insurance reform, entitled the “Autism Treatment Acceleration Act of 2008.”

FAQ: What does ‘least restrictive environment’ mean?

Your child’s education must be in the least restrictive environment or "LRE". LRE means that placement of students with disabilities in special classes, separate schools or other removal from the regular educational environment occurs only when the nature or severity of the disability is such that, even with the use of supplementary aids and services, education cannot be satisfactorily achieved.

In all cases, special education services should be provided in the least restrictive environment. Each year your child’s IEP should be developed to ensure that:

- your child’s placement is based on his or her IEP.
- your child’s placement is as close as possible to his or her home. Unless your child’s IEP requires another arrangement, your child should be educated in the school he or she would have attended if he or she did not have a disability.
- when making a decision about LRE, the Committee considers any possible harmful effect on your child or the quality of the services that he or she needs.
- your child is not removed from education in a regular classroom with other children of the same age only because the general curriculum needs to be modified.

A letter from the editor……commentary for Journey of 1000 Miles

Dear Readers,

I am writing this editorial for the article printed on the next page written by Rick Lavoie for a Boston newspaper.

As the Presidential campaign unfolded, I and other parents I know found themselves upset at the idea that Governor Palin was promising special needs parents a friend in the White House if they voted for her and Senator McCain.

First and foremost, one would think that parents and children with special needs <u>always</u> have a friend in the White House. I didn't know they didn't! A global thinker need not be in the same circumstances to be sympathetic. I would hope that our country's leader is at least a global thinker!

As the parent of a child with special needs you meet so many others who deal with some of the same problems. You will meet those who handle more than you could imagine even with your own trials. You will meet those who seem to have less of a burden or more success from the choices they make for their kids.

Whatever the situation, each parent, each family, has their hands full. Once they finish mourning the loss of the baby they thought they would have they begin to try and identify the issues and spend many sleepless nights looking far into the future. You pray, you try, you hope that every decision you make is the right one-the one that will change something for your child and make their life better...and yours easier.

Children's disabilities are so varied, so complex, so completely different, and yet we are all grouped together. Maybe it's a good thing. Some days, each other is all we have. Well meaning friends and family so often "just don't get it". Or if they do, they don't get the full gamut of how your child's needs affect you on every possible level. You are forever changed and your life's path takes a sharp turn into unknown territory.

You learn a whole new vocabulary. You try to decipher what medical professionals, psychiatrists and educators say with such ease because it is within their scope of preparedness. Nothing in your experience has prepared you for any of it! And you have to decide when you know better than they do... because you know your child.

I felt that Rick Lavoie touched on most of the things I was thinking as this Governor, this candidate, this mother, equivocated herself with other parents of special needs children. What I think he failed to point out, is not only does she not yet know what these parents endure and overcome simply from her obvious lack of experience, but that she might *never* truly know.

I doubt that Governor Palin will experience the financial struggles that most families do when trying to pay for doctors, evaluations and testing. I can't imagine that once she does know what her beautiful, adorable baby's limitations are, she will have the exhausting battle to secure therapists, fights with insurance companies, or school districts.

I find it hard to believe that people will be as unkind to her and her family because of her social standing. Finding a caretaker she can trust and afford so she has some freedom shouldn't be a problem.

I can not imagine educators refusing the Governor services. I can't imagine her losing services because her child reached an incredibly still below average percentile because that is where the cutoff line is.

That being said, I do believe that it was said with the best of intentions just with a lack of knowledge. She is in ***her*** infancy of being a special needs parent and if you try to remember your own time, you were probably as naive. Or maybe she just needed to be grouped together with us so that she doesn't feel so alone.

We at Massapequa SEPTA know that we are more fortunate than most of the parents like us across Long Island alone. We really do support each other and are there for each other when no one else "gets it".

I thank you all for that comfort and for all that you do for the children in our district. May the Governor be so lucky in her town.

Deborah Fauci-Giaquinto

Editor in Chief

For more of Rick Lavoie's work, please visit www.ricklavoie.com

Governor Palin's Journey of 1000 Miles

By Rick Lavoie

As an advocate for families of handicapped children for over three decades, I have taken a special interest in the role that Trig Palin is playing in the Presidential campaign. Trig, now six months old, is nominee Sarah Palin's son.

He has Down Syndrome. Governor Palin often tells her audience that she will be a champion for "special needs families" because "she knows what you're are going through."

With great respect and empathy, I must say, "Sorry, Governor, but you don't." You will…someday. But not now. Not yet.

Trig is – and always will be – a blessing in your family's life. But, Governor, your journey has just begun. You *will* understand…someday. But between that day and today, there will be a lot of other "somedays."

Someday…you and your family will spend stressful hours in a hospital waiting room while Trig undergoes corrective surgery. The doctors will call it "routine"…but that characterization will seem foreign and insensitive to you.

Someday…a relative or "close friend" will suggest that Trig not be brought to a holiday function because "it may be too much for him to handle." Your relationship with that person will never be exactly the same again.

Someday…all the students in his class will be invited to a birthday party…except Trig.

Someday…some stranger in a store will stare at him and ask an insensitive and intrusive question. Startled, you will give a bland response. But for several days after the incident, you will generate great and clever retorts that you "should have said." (By the way, you won't be able to recall these "clever retorts" the next time this occurs).

Someday…your adorable daughter who stroked Trig's hair during the GOP convention will grow into adolescence. Trig will embarrass her in front of her friends and she will tell you, "I hate him! I hate him! I hate him!" (…she will feel guilt-ridden after her rant and will cry herself to sleep that night).

Someday…you will have to place him on the special bus.

Someday…you will recognize that toilet training will take *years*…not months.

Someday…he will sob bitterly in his bed and you will hug him tightly. But he will be unable to tell you where his pain is coming from.

Someday…you and your husband will decide to take separate vacation plane flights because of your gut wrenching fear of what would ever happen to Trig if the two of you were to die together.

Someday…you will take Trig on a long and expensive journey to meet and be examined by a "professional" who claims that he can "cure" your son. After weeks of "therapy" you will realize that the approach is baseless and you will wish that you had invested the funds in tutoring and counseling.

Someday…you will – inexplicably and irrationally – blame your husband for Trig's plight and you will have an intense and hurtful argument. You will apologize later…but the damage will have been done.

Someday…you will deny the severity of Trig's problems and you will insist that he be allowed to participate in challenging academic or social programs. He will fail miserably and publicly. You will be greatly guilt-ridden.

Someday…you will begin researching long-term housing for Trig when he reaches adolescence. You will learn that there is a 5000-person waiting list for placement.

Someday…you will take him out for a special dinner on his Prom Night and you will hope that you can take his mind off the event that he is missing.

Someday….you will sit down with his siblings as they are building their adult lives and explain that they must also plan to play an ongoing role in Trig's life because *Mom and Dad will not live forever*.

Most "special parents" I know have lived these "somedays". They recognize – as you will, Governor- that raising a special needs child also has great blessings, triumphs, victories and golden moments. You will meet extraordinary people on this journey.

Governor Palin, my thoughts, prayers and best wishes are with you on this journey. I suggest that you contact other special needs parents and talk to them. They are a remarkably generous group. Learn from them. Listen to them. Lean on them. But don't try to lead them. Not yet. You're not ready.

Governor, I pray you will be ready…someday.

Massapequa SEPTA Recommendation Form for 2009-2010

Each office holds a one (1) year term with a two (2) year maximum. All positions need to be filled. The VP for Membership has held a two year term and is not eligible for re-nomination to the same position. All other positions have held one year terms and are eligible for re-nomination to the same position. According to bylaws Article VII, Section 2d, 'No person shall hold more than one office at the same time'.

Please write down your suggestions as to whom you feel would best fill each seat. More than one name can be suggested for each position, including your own! Please add any comments you many have by attaching a separate paper including whether you would like to be considered for a position. Please keep in mind that while recommendations can be requested, it must be understood by all that they are **not** binding on the part of the Nominating Committee. The Committee must take all facts into consideration while deliberating to choose the best-qualified person for each job. Initial recommendations must be presented at the **MARCH 10, 2009** SEPTA meeting, so please reply quickly. We Value YOUR input, and YOUR volunteering!

*President/Co-President:*____

Previous Experience: ____

*(If Co-President, must list two names) Co-President*______________________________

Previous Experience: ____

VP Programming: ____

Previous Experience: ____

*VP Membership:*____

Previous Experience: ____

*VP Fundraising:*____

*Previous Experience*____

*Treasurer:*____

*Previous Experience*____

*Recording Secretary:*____

*Previous Experience*____

Corresponding Secretary: ____

Previous Experience: ____

Please return this form in a SEALED envelope clearly marked NOMINATING COMMITTEE to :

Christine Ophals, Chairperson Nominating Committee

271 Ocean Avenue

Massapequa Park, NY 11762

How much do you know about Tourette Syndrome?

Tourette Syndrome (TS) is a neurological disorder characterized by tics-involuntary, rapid, movements or vocalizations that occur repeatedly in the same way. Most people with TS do have some control over their symptoms. What is not known is that the control, which can be exercised anywhere from seconds to hours at a time, may merely postpone more severe outbursts of symptoms. Tics are experienced as irresistible and (as with the urge to sneeze) eventually must be expressed. People with TS often seek a secluded spot to release their symptoms after delaying them in school or at work. Typically, tics increase as a result of tension or stress, and decrease with relaxation or when focusing on an absorbing task. Genetic studies indicate that TS is inherited causing different symptoms in different family members and is more common in males than females.

Is obscene language (coprolalia) a typical symptom of TS? Definitely not. The fact is that cursing, uttering obscenities, and ethnic slurs are manifested by fewer than 15% of people with TS. Because milder cases are being diagnosed, the incidence of coprolalia will probably decrease.

What are the first symptoms? The most common first symptom is a facial tic such as rapidly blinking eyes or twitches of the mouth. Involuntary sounds such as throat clearing and sniffing, or tics of the limbs may be initial signs. For a minority, the disorder begins abruptly with multiple symptoms of movements and sounds.

How is TS diagnosed? Diagnosis is made by observing symptoms and by evaluating the history of their onset. No blood analysis or other type of neurological testing exists to diagnose TS. Some physicians may wish to order an EEG, MRI, CAT scan, or certain blood tests to rule out other ailments that might be confused with TS. Rating scales are available for assessment of tic severity. The range of tics or tic-like symptoms that can be seen in TS is very broad. The complexity of some symptoms is often perplexing to family members, friends, teachers and employers who may find it hard to believe that the actions or vocal utterances are involuntary.

Is it important to treat Tourette Syndrome early? Yes, especially in those instances when the symptoms are viewed by some people as bizarre, disruptive and frightening. It is also important to consider therapy when the child is concerned over her/his acceptance to peers. Sometimes TS symptoms provoke ridicule and rejection by peers, neighbors, teachers and even casual observers. Parents may be overwhelmed by the strangeness of their child's behavior. The child may be threatened, excluded from activities and prevented from enjoying normal interpersonal relationships. These difficulties may become greater during adolescence -- an especially trying period for young people and even more so for a person coping with a neurological problem. To avoid psychological harm, early diagnosis and treatment are crucial. Moreover, in more serious cases, it is possible to control many of the symptoms with medication.

Do students with TS have special educational needs? Children with TS as a group have the same IQ range as the population at large, many have special educational needs. Data show that many may have some kind of learning problem. Combined with attention deficits and the difficulty coping with frequent tics, often call for special educational assistance. The use of tape recorders or computers for reading and writing problems, un-timed exams (in a private room if vocal tics are a problem), and permission to leave the classroom when tics become overwhelming are often helpful. Some children need extra help such as access to tutoring in a resource room.

When difficulties in school cannot be resolved, an educational evaluation may be indicated. A resulting identification as "other health impaired" under federal law will entitle the student to an Individual Education Plan (IEP) which addresses specific educational problems in school. Such an approach can significantly reduce the learning difficulties that prevent the young person from performing at his/her potential. The child who cannot be adequately educated in a public school with special services geared to his/her individual needs may be best served by enrollment in a special school or home schooled.

People with TS can have associated behaviors in addition to tics such as

*Obsessions which consist of repetitive thoughts which can become unwanted or bothersome.

*Compulsions and Ritualistic Behaviors which occur when a person feels that something must be done over and over or in a certain way. Examples include touching an object with one hand after touching it with the other hand to "even things up" or repeatedly checking to see that the flame on the stove is turned off. Children sometimes beg their parents to repeat a sentence many times until it "sounds right." Repetitive copying and erasing of work in school can be quite disabling.

*Attention Deficit Disorder with or without Hyperactivity occurs in many people with TS. Children may show signs of hyperactivity before TS symptoms appear. Indications of ADHD may include: difficulty with concentration; failing to finish what is started; not listening; being easily distracted; shifting constantly from one activity to another; needing a great deal of supervision; and general fidgeting.

*Learning Disabilities may include reading and writing difficulties, problems with mathematics, and perceptual problems.

*Difficulties with impulse control which may result, in rare instances, in overly aggressive behaviors or socially inappropriate acts. Also, defiant and angry behaviors can occur.

*Sleep Disorders are fairly common among people with TS. These include difficulty getting to sleep, frequent awakenings or walking or talking in one's sleep.

Weighing Non-drug Options for A.D.H.D. *by Tara Parker-Pope NY Times*

About 2.5 million children in the United States take stimulant drugs for attention and hyperactivity problems. But concerns about side effects have prompted many parents to look elsewhere: as many as two-thirds of children with A.D.H.D., have used some form of alternative treatment.

The most common strategy involves diet changes, like giving up processed foods, sugars and food additives. About 20 percent of children with the disorder have been given some form of herbal therapy; others have tried supplements like vitamins and fish oil or have used biofeedback, massage and yoga.

While some studies of alternative treatments show promise, there is little solid research to guide parents. That is unfortunate, because for some children, prescription drugs aren't an option. The drugs have been life-changing for many children. But nearly one-third experience worrisome side effects, and a 2001 report in The Canadian Medical Association Journal found that for more than 10 percent, the effects could be severe-including decreased appetite and weight loss, insomnia, abdominal pain, and personality changes. Although the drugs are widely viewed as safe, many parents were alarmed when the FDA ordered in 2006 that stimulants like Adderall, Ritalin and Concerta carry warnings of risk for sudden death, heart attacks and hallucinations in some patients.

What about the alternatives? Last week, The Journal of the American Medical Association reported that the first study of the herb St. John's wort worked no better than a placebo to counter A.D.H.D. But the trial, of 54 children, lasted only eight weeks, and even prescription drugs can take up to three months to show a measurable effect.

But the larger issue may be that in complementary medicine, one treatment is rarely used alone, making the range of alternative remedies difficult to study. Natural treatments may well be beneficial, said the report's lead author, Wendy Weber, a research associate professor at the school of naturopathic medicine at Bastyr University in Kenmore, Wash. "We just need to do more studies and document the effect."

Other herbal treatments for the disorder include echinacea, ginkgo biloba and ginseng. There are no reliable data on echinacea; a 2001 study showed improvement after four weeks in children using ginkgo and ginseng, but there was no control group for comparison. There is more hope for omega-3 fatty acids, found in fish and fish-oil supplements. A review last year in the journal Pediatric Clinics of North America concluded that a "growing body of evidence" supported the use of such supplements for children with A.D.H.D.

As for dietary changes, 2007 study in The Lancet examined the effect of artificial coloring and preservatives on hyperactive behavior in children. After consuming an additive-free diet for six weeks, the children were given either a placebo beverage or one containing a mix of additives in two-week intervals. In the additive group, hyperactive behaviors increased.

The study caused many pediatricians to rethink their skepticism about a link between diet and A.D.H.D. "The overall findings of the study are clear and require that even we skeptics, who have long doubted parental claims of the effects of various foods on the behavior of their children, admit we might have been wrong," reported a February issue of AAP Grand Rounds, a publication of the American Academy of Pediatrics.

Data on sugar avoidance is less persuasive. Several studies suggest that any link between sugar and hyperactivity is one of parental perception, rather than reality. In one study, mothers who were told the child received sugar reported more hyperactive behavior, even when the food was in fact artificially sweetened. Mothers who were told the child received a low-sugar snack were less likely to report worse behavior.

One interesting option is a form of biofeedback therapy in which children wear electrodes on their head and learn to control video games by exercising the parts of the brain related to attention and focus. Research has suggested that the method works just as well as medication, and many children report that they enjoy it.

The challenge is finding a doctor who will help explore the range of options. For instance, the best way to tell whether dietary changes may help is to eliminate the foods and then reintroduce them, monitoring the child's behavior all the while. The best evidence may come from a teacher who is unaware of any change in diet.

The Integrative Pediatrics Council, at www.intergrativepeds.org offers a list of pediatricians who offer alternative treatments. Its chairman, Dr. Lawrence D. Rosen, chief of pediatric integrative medicine at Hackensack University Medical Center in New Jersey, says parents should seek a holistic approach. But he notes that that may well include prescription drugs.

"I do prescribe medications in my practice, and there are kids whose lives have been saved by that," he said. "But it's a holistic approach that is very different than one pill, one symptom. We're addressing not just the physical, chemical needs of kids, but their total emotional and mental health"

What is Assistive Technology?

Assistive technology (AT) is any kind of technology that can be used to enhance the functional independence of a person with a disability. Often, for people with disabilities, accomplishing daily tasks such as talking with friends, going to school and work, or participating in recreational activities is a challenge. AT devices are tools to help to overcome those challenges and enable people living with disabilities to enhance their quality of life and lead more independent lives.

Assistive technology can be anything from a simple (low-tech) device such as a magnifying glass, to a complex (high-tech) device, such as a computerized communication system. It can be big — an automated van lift for a wheelchair — or small — a grip attached to a pen or fork by Velcro. Assistive technology can also be a substitute — such as an augmentative communication device that provides vocal output for a child who cannot communicate with her voice.

It is important for parents to understand the “language” of assistive technology so they can be informed advocates for their child’s technology needs. The glossary of terms that can help parents learn about the kinds of assistive technologies there are and how they can be used is currently available at the Family Center on Technology (FCTD) website, www.fctd.info.

Assistive technology is a part of the Individuals with Disabilities Education Act (IDEA) and should be included on your child’s IEP. The IEP team determines the AT needs of the child through an assessment process. It is important to consider the child’s strengths as well as their weaknesses, their likes and dislikes, and what strategies are helpful in interacting with the child. A child’s AT needs will change depending on their environment — at home, at school, or out in public at a library or at the mall— so the perspectives of family members and teachers, as well as the student, should all be taken into consideration.

If the IEP team is unable to determine what AT devices and services are best for your child, then a formal AT evaluation may be needed. The evaluation should be performed by a qualified professional in a timely fashion. This may present a problem, as there is a shortage of qualified AT evaluators in many areas of the country. The school system may choose to use its own personnel to conduct the evaluation, but if parents disagree with the recommendations, they have the right to an independent evaluation at district expense. Be aware, however, that parents may have to assume the cost of an independent evaluation if the results do not differ from the one provided by the school system and if the system can show that the original evaluation was appropriate.

25 ***Great*** Things About ADD by Bob Seay

Insomnia makes for more time to stay up and surf the net.

The drive of HYPERFOCUS.

Resiliency.

A sparkling PERSONALITY.

Generosity with money, time and resources.

INGENUITY.

A strong sense of what is *FAIR*.

Willingness to take a RISK.

Making far-reaching analogies that no one else understands.

SPONTANEITY.

Possessing the mind of a Pentium-with only 2 MB’s of RAM.

Pleasant and constant surprises due to finding clothing for (or money or spouses) you had forgotten about.

Being *FUNNY.*

Being the last of the **ROMANTICS.**

Being a good conversationalist.

An innately better understanding of intuitive technologies such as Computers or PDA’s.

Honestly believing that *ANYTHING* IS POSSIBLE.

Rarely being satisfied with the status quo.

Compassion.

Persistence.

Joining the ranks of artists, musicians, entrepreneurs, and other creative types.

Always being there to provide a different perspective.

Willingness to fight for what you believe in.

Excellence in MOTIVATING OTHERS.

Being highly organized, punctual and generally responsible. (OK, I lied.)

Massapequa SEPTA serves every family who receives special education services in our school district.

Massapequa Special Education

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LD Online is the world's leading website on learning disabilities and ADHD. They have a wealth of information and helpful reading presented in an easy to read, easy to understand format.

www.ldonline.org

All About Adolescent Literacy is a website launched by Reading Rockets and LD online. This website is an excellent resource for parents and educators of students with reading difficulties in grades 4 through 12.

Please visit

www.Adlit.org

Contact the Editor!

Please feel free to contact the editor with any comments or suggestions.

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FYI

Nassau Region PTA Legislation Brunch

March 7, 2009

Brunch will be served in Woodbury and SEPTA will be represented. If you are interested in attending, please contact

Bonnie Goess at 541-1754