

# ADHD news

ADD Information Services (ADDISS) Registered Charity No 1070827

SPRING 2003

## First UK ADHD Parent / Carer Consultation Convention *Parents, Provision and Policy*

  
*Southport*  
Daytime, Night time, Great time!

6th and 7th September, 2003

Southport Theatre and Floral Hall

A large number of parents and carers of children and young adults with ADHD are expected to attend the first ever parent and carer convention in September 2003, in the seaside resort of Southport. Parents will come together to share their experiences, views and concerns about services provided for children and young adults with ADHD. These views will be collated and presented to the relevant government departments and ministers in a manifesto.

This convention has the support of many professionals, but most importantly representatives from the Department for Education and Skills will be in attendance, together with members of the National Service Framework for Children sub group, the

Children's Taskforce and many other interested parties.

The Government is keen to build a culture of consultation with user groups. To date the NSF for Children, together with the Children's Taskforce, which is responsible for looking at mental health services for children and young people are planning services and making decisions without consulting the parents, carers, user groups and voluntary agencies most directly involved with ADHD. The majority of referrals to Child and Adolescent Mental Health Services (CAMHS) are ADHD related, and for this reason we feel this consultation exercise is urgently needed.

High profile speakers at this event will include **Professor Eric Taylor, and Fintan O'Regan.** We

are also lucky to have secured **Jerry Mills**, who will be coming from the USA specifically to be with us and to give his inspirational keynote presentation. **DON'T DOUBT THE DREAM.** However, most importantly this is an opportunity for you all to have your say. We want to have your views on gaps in service provision for children with ADHD and enable meaningful discussion on the way services can be improved and developed.

Between presentations we will break into groups for discussions on the following topics.

Health  
Social services  
Education  
Transition to adult services  
Treatment of young offenders  
**(We are pleased to welcome the Lancashire Police who will be facilitating a discussion on ADHD and Youth Offending).**

For further information visit our website [www.addiss.co.uk](http://www.addiss.co.uk), contact ADDISS or your local support group. You will have an



opportunity to meet other parents and carers, share your views and ideas and learn more about support groups and ADHD projects nationally.

If we are really going to bring about change it is crucial for parents and carers to make their views known to those agencies responsible for providing services for children and young adults with ADHD. The cost of this convention will be no more than £30 per person and we are hoping to organise coaches for large parties wishing to attend.

**Stand up and be counted.  
BOOK NOW! - see back page.**

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## Translating ADHD: The

By Dr. Ron Weinstein, Ph.D.



Many of the arguments and the resulting rages or temper tantrums that arise between family members can often be traced to differences in perception and communication style. How we see and make sense of the world around us influences how and what we communicate to others. This usually becomes quickly apparent to anyone involved in a relationship with someone who has ADHD. Therefore, developing an understanding and being sensitive to these communication differences are essential for successful relationships.

As a specialist in AD/HD, learning and behavioural difficulties, I work with children, adults, couples and families in numerous capacities from initial assessment to developing specific ways of living. My experiences are often "in the trenches", as a consultant to schools, as a coach when emotional support is needed, as an advocate in legal battles, or as an objective observer in the heat of family battles, helping to prioritize issues that are causing unbearable discomfort. In many cases, I have to act as an interpreter!

I am fortunate to have been armed with extensive professional knowledge and experience of AD/HD, have raised a child with AD/HD and was diagnosed with AD/HD myself almost 12 years ago. I've been able to work on my own life and relationships with a clearer understanding of the differences between communication styles and use this knowledge to help my clients resolve issues that may have dissolved relationships in the past.

It's not difficult to understand how the "triad" of AD/HD symptoms — impulsivity, inattention and hyperactivity/restlessness, can affect relationships. However, I believe that these "visible symptoms" have somewhat less direct impact than the ways in which they have indirectly affected a variety of "hidden" developmental characteristics.

Most adults with AD/HD for example, were not diagnosed until they were adults. Throughout their lives, they have suffered a great deal of pain. Many have had to develop coping mechanisms to help them survive. Over time, the constant pressure of trying to cope with their problems brought on by their new ways to cope can bring about stress. As a result, some adults become overwhelmed, depressed, anxious and lose confidence. Since we can't go back and

change this history, we need to move forward and realise that the effort we put into our personal growth creates hope for a changed life. Newly diagnosed adults finally have the opportunity to closely examine their lives in a more reflective and meaningful manner and to understand why they made the choices they did. But as we are aware, just understanding doesn't guarantee anything will change.

All individuals with AD/HD therefore need to understand who they are. We need to help them identify their strengths, their weaknesses, and the hurdles they have to overcome in life.

### Who are you?

At the initial consultation, one of the first things I ask an adult client is — "Who are you?" This usually catches them off guard. They might have thought about the concept during times of turmoil, but for the most part, the question never entered their minds. Are they comfortable with their "gut" reactions to things? Do they believe that what they feel is appropriate? Do they often feel guilty about not doing something or harbour resentment if they do?

Individuals with AD/HD typically have a problem identifying who they "really are" since throughout their lives they've tried to change their personalities to fit the

situation at hand or to be accepted as part of the group. Adding to this confusion is the fact that they can't often trust what they feel since their reaction to situations was often "different" than what was considered the norm. As a result they may pretend for example, they are wise and sophisticated but, at the same time, are waiting to be "found out" when the "bubble bursts"!

### Making Sense of Interpersonal Communication

Good communication depends on people understanding one another's true thoughts, regardless of the words they happen to be using. Since our brains work so much faster than our mouths, we often use a kind of shorthand, which might have an entirely different meaning for another person than it does for us.

The understimulated brain of someone with ADHD is like a wind-up watch that requires self-stimulation periodically throughout the day. This non-stop circulation of thoughts and ideas in the brain of a person with ADHD provides this stimulation and is a wonderful source of creativity, but it often creates difficulties with communication. It's as if individuals with ADHD must contend with a three-ring circus performing in their heads — they

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# Key to Communication

are trying to pay attention to the sound of the other person's voice and are concentrating their efforts to get meaning from the person's words. At the same time they're becoming aware of the freedom to or fear of saying what they are feeling and as a result, the more involved they are in trying to be less distracted, the less involved they are in the conversation!

## Words and meanings are not always the same.

From my experience, it seems clear that many of the difficulties experienced in relationships result from the fact that the meanings of the words spoken and the priorities placed on tasks are quite different for the individual with ADHD. It's as if they speak a different language. This results in miscommunication, misinterpretation and misunderstanding! Thus I often hear, "That's not what I meant!" or "You don't understand!"

Problems with word storage and retrieval also cause misunderstanding. Individuals with ADHD often have difficulty maintaining an organised "filing" system since the ADHD brain creates so many options. You must know where a word is "mentally filed" in order to retrieve it. For example, a person with ADHD may file the word "apple" under the letter "A" or "F" for fruit, or even "R" for round or red and so on. She may file it differently every time. However, the person who does not have ADHD will probably file the word the same way each time, under the most universal choice — A for apple.

This disorganised filing system impacts communication in a big way, causing him to seem hesitant or unsure while he searches through his mental file cabinet for the right word or phrase. During this time, the "lottery ball effect" takes over. Instead of numbered balls flying around until they drop down the tube, a word, idea or fragment of

an incomplete thought may randomly and impulsively come out of the individual's mouth. What comes out of the mouth is often a surprise even to the person who said it!

This happens because of the difficulty isolating individual thoughts in a brain that's constantly being filled with new ideas. The spoken word only becomes real when it is uttered aloud. It is only after the word leaves the mouth that the ADHD individual can decide whether or not it makes sense, and whether or not it's appropriate. If it is inappropriate, he may then respond by saying, "Oh, I didn't mean that!" Oftentimes however, the recipient of the remark has difficulty believing he didn't mean it, especially if inappropriate remarks are made frequently.

## Priorities

The level of importance we place on something determines our priorities. In my clinical experience, many families have never even considered that their different priorities can profoundly affect their relationships. For instance, simple day-to-day activities that require planning and organising may not be high priority tasks for someone with ADHD. A task that is more stimulating, or one to which he may respond in a more extreme or "emotional" manner, is more likely to be a higher priority.

Differences in priorities and time urgencies are often reflected in the "no big deal" response. For example, walking past a bag of garbage without picking it up, leaving the lawn covered with leaves, or even driving past the library with overdue books and not returning them may not make any sense to some. In the mind of someone with ADHD however, it is "no big deal", since "it will get done eventually."

## Becoming Aware, Accepting Our Differences and Developing an Action Plan

Individuals with ADHD are complex. Adding to this inherent complexity are the emotional defenses resulting from years of being misunderstood and not trusted or believed. One goal is to be aware of what triggers these defenses, thereby reducing anxiety and anger, which allows the individual to incorporate the tools for improving interpersonal relationships.

Acknowledging and accepting differences helps the individual with ADHD feel respected as a separate person. Only at that point, can the process of successfully negotiating differences and working on those issues or behaviours that may be inappropriate begin.

An "action plan" usually involves change, either in behaviour, attitude, environment, or responsibility. Change is an essential part of life, yet one which can be extremely painful for many people. There is not much hope for a relationship in which one person takes no steps to change. Often, I find that in adult relationships the non-ADHD person is more hesitant to change, because it has been easier to blame all past problems on his/her partner's ADHD. On the other hand, many partners with ADHD often believe that their partner must accept ADHD as an "excuse" for certain behaviours.

Neither partner in a relationship has to accept unacceptable behaviour. When a person who does not have the disorder seeks a support group to help deal with a partner with ADHD who is sloppy, has frequent outbursts, or is unable to hold a job, in some cases, my advice is to forget it! Behaviours that lead to disorganisation, screaming or unemployment can be changed, but only if the person with the problem is able and willing to make an effort to change. If

he/she is not, I suggest re-thinking the reasons for remaining together.

Getting out "poisonous" feelings like resentment and anger is important, yet it's often difficult when one or both partners have a hard time keeping quiet or listening without interrupting. I use and suggest "a 2 & 2 emotion dump" — two minutes for each person to write on paper or via email about how they felt that day, what may have bothered them or share positive experiences. I suggest using "I" statements, reflecting how the person writing feels, rather than what he/she perceives has been done to him/her by others. Since this format is not face-to-face, neither partner can interrupt, be distracted by the other's words, or impulsively make a judgment leading to a blowup.

Another tool which helps gain clarity in the relationship is the Top Priorities List. Each partner compiles a list of what he or she feels are the most important daily and long-term issues to be dealt with. In many cases, the long-term priorities are similar. However, the differences in daily priorities are typically great. What the adult with ADHD may consider "top priorities" is often in direct opposition to what the non-ADHD partner gives weight to, revealing possible causes of tension.

Essentially, mutual trust is fundamental in a relationship that works. Mutual trust is based on the ability to correctly interpret what our partner is trying to communicate and vice versa. That process is the one that takes the most work, but as I tell my clients, life never gets any easier; we just hope to get better at dealing with it!

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# ADDISS

2 0 0 2 C O N F E R E N C E

At the Royal National Hotel, Russell Square, London

ADHD: The First Century of Understanding 4-5-6 November 2002

**I** love arriving at an ADDISS conference. You can feel this tremendous buzz and energy! Maybe it comes from the Hyperactivity of some of the attendees or maybe it's just the strong desire for positive outcomes for a disorder that causes maximum challenges in many homes throughout the land.

The Conference opened with an address from Lady Astor of Hever an ADDISS Patron who has an ADHD child. She spoke about the need for the World to be accepting of its more eccentric people and not require everyone to be stolid and grey. Lady Astor also mentioned that ADDISS is about to begin an affiliation programme where support groups will be able to affiliate, after an inspection process to ensure that any information they are sending out as is as up to date and accurate as possible.

**Dr Geoff Kewley of the Learning Assessment Centre in Horsham then introduced Professor Eric Taylor, Head of the Child Psychiatry Department of the Institute of Psychiatry in London – The George Still Memorial Lecture.**

Professor Taylor is highly regarded as a specialist in the area of ADHD and is currently running a very large project in the East End of London where he is tracking and analysing the progress of more than 2,000 children some of whom have ADHD. These children have been monitored and checks taken at 7 and 17 years old. I believe they will be analysed again in their twenties. The statistics from this study will help to inform the future service requirements of the UK ADHD population. We were able to see many of the monitoring statistics during his talk.

George Frederick Still, born in 1868, was the British Doctor credited with first describing what later became known as ADHD. In a lecture at the Royal College of Physicians



*Lots of goodies for the delegates*

in March 1902, which was later reported in The Lancet, he described how he was studying a group of children whose behaviour was characterised by a tendency to be: 'passionate, deviant, spiteful and lacking inhibitory volition'. Doctor Still himself was described as reserved, austere and unapproachable, except when he was with children.

Professor Taylor went on to discuss how ADHD knowledge and terminology has evolved in the last 100 years. We now have a better understanding of the proven and potential causes of ADHD, better definitions and terminology, effective medications, greater research into the genetic and biological side, but still no physical diagnostic test. Professor Taylor stated that there was still patchy access to services for people with ADHD, with many Primary care givers still not recognising it or even denying its existence. There is also a lack of communication between professionals, which also perpetuates the fragmented service. He said that there was a dearth of services for Adults with ADHD.

**The second speaker was Professor Keith Connors, Professor Emeritus of Medical Psychology at Duke University Medical School** and the originator of the famous Connors Rating Scales and Connors Continuous Performance Test. Prof Connors gave more historical background material and another fact filled speech. Some interesting

points from this included the fact that Hyperactivity doesn't really disappear but becomes more internalised with age leading to restlessness and nervousness. People with ADHD are more likely to suffer from Occupational, Vocational, Relationship and Legal difficulties than the average person. They are also more likely to be involved in car and other accidents, smoking and substance abuse and have very low self-esteem. Their parents don't come off lightly either because they suffer extra stress, worry, frustration, anxiety, anger, low self esteem, social isolation, depression and have increased employment disruption, marital problems and alcohol and substance abuse! Funnily enough, children with ADHD who are properly medicated are 3 times less likely to abuse substances. He also suggested likely co-morbid conditions that can be found alongside ADHD as in 10% may have Conduct Disorder, 40 to 50 % Oppositional Defiant Disorder, 5 to 25% Mood Disorder and 35% Anxiety Disorder. Prof Connors talked about the three components of ADHD treatment; Education including parent training, Behaviour management, and Medication management. A recent study showed that a combined approach using all three gained the best results in reducing core symptoms.

*One of the biggest problems at an ADDISS conference is choosing which of the dozen or so parallel sessions to attend throughout the day. So many high quality speakers, so many interesting aspects: some workshops are targeted at medical professionals, some for people working in the Justice system, some are for Support Groups, some more for parents and families, some are about ADHD adults and some deal with a variety of therapies. It's like trying to choose two or three favourite chocolates from a big box!*

*I can therefore only mention brief details of those particular workshops I was able to attend.*



**ADHD, the SEN Statement, the Tribunal and the Law – Dr Ron Weinstein – Executive Director of The Young Options Institute**

Dr Weinstein talked us through the Statementing process and the Revised Code of Practice. He said it sets out policies and procedures aimed at enabling pupils with SEN to reach their *full* potential and to be *fully* included in their school communities and make *successful* transitions into adulthood.

He discussed the specific problems that students with ADHD have educationally which include faults in their working memories, which is what gives us a sense of time both past and future; if you have no past, you can't imagine a future and are also unable to learn from past mistakes because you don't remember them. Functional impairments often noticed by teachers include an inability to get along with peers, getting into fights, inappropriate social skills, failing to finish work, no homework done, can't complete projects, problems with receptive and expressive language and really require constant 1 to 1. He discussed the School Action Plan, IEP's and School Action Plus. In IEP's it is important to ensure that any goals set are age and academically appropriate. It interested me to discover that only if a parent asks for a Statutory Assessment by the Local Authority can it be appealed against if the outcome is not what you wanted; if the School or other Professional has asked for the Assessment there I no right of Appeal.

All of these workshops are very full sessions and Dr Weinstein clarified some important points about the Statementing process. Should anyone reading this be considering asking for one they would be well advised to consult someone like Dr Weinstein who hasn't lost a Tribunal yet! Contact details at the end of this article.



Dr Ron Weinstein



Dr Thomas Phelan

**ADHD and Family Stress – Dr Thomas Phelan – Clinical Psychologist and Lecturer and creator of 123 Magic – effective Discipline for Children from 2-12.**

Dr Phelan is both an ADHD professional and father of an ADHD adult son. He is a very funny and entertaining speaker and the creator of 123 Magic, which is a behaviour management method that is easy to use and works.

He talked about parents and thinks good parents are both warm and demanding. You shouldn't be afraid to have expectations of your children but just to remember that they have ADHD and maybe modify them a little. Some of his management strategies include having a regular routine for homework so that it becomes a set habit. Getting up problems he feels should be left to natural consequences to take over. If they stay in bed, then they have to take the consequences of that by facing their teacher or headteacher and explaining their lateness by themselves; no excuse notes. He also indicated that if meal-times were a problem then eat separately; there is no law that says families have to eat together. Dr Phelan graphically illustrated all his talks with incidents that happened within his own family as the children grew up. He was very, sympathetic, understanding and very, very funny.

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*At the end of Day 1 I felt pleasantly shattered! Lunch had been lovely, during which I sat and talked with a doctor called Elizabeth from Norway who specialises in treating girls with ADHD. I was disappointed in not being able to attend all the workshops but if I was this tired after 2 lectures and two workshops I'd have been dead after more!! I would have really liked to learn more about Coaching, Emotional Intelligence and the Gap between Theory and Practice, to name but a few.*

## DAY 2

**Neurobiology of the Brain – Dr John Ratey – Associate Clinical Professor of Psychiatry at Harvard Medical School.**

Dr Ratey showed us slides of his ADHD dog and quoted Yogi Bear. Again, he made a complex subject funny and interesting, at one point telling us that even Moses was ADHD because he took the Tablets! He also talked about the genetic side of ADHD and the links being found by gene hunters that connect certain genes to ADHD, such as the D2 receptors gene which is the alcohol gene, and the D4 receptor which is the novelty seeking gene. As this time there were more professionals among the delegates than parents and non-professionals so that it was especially interesting to listen to the questions at the end. Many more doctors and psychiatrists are showing a keen interest in learning more about ADHD – thank heavens.

**The Co-Morbidities of ADHD – an Under-rated Problem – Professor Chris Gillberg, a Professor of Child and Adolescent Psychiatry at the University of Gothenburg in Sweden**

A number of Swedish studies confirm that the estimate of ADHD in the population could be around 7% with 3% at the severe level. Girls are still vastly under-diagnosed and are more likely to attract diagnoses of Eating Disorders, Anxiety, Depression and Borderline Personality Disorder than ADHD.

Many other disorders run alongside ADHD and can include 20 to 50% with reading and writing disorders, 20% with a Maths disorder, 50% developmental Coordination Disorder, 30 to 50% language delay and deficits in motor control and perception, 15% learning disabled and 90% have academic failure relative to their IQ. He feels that ODD should be seen as a symptom of severity in ADHD rather than a separate disorder.

**How to Survive Your Adolescents – Dr Thomas Phelan – Clinical Psychologist and Lecturer and creator of 123 Magic – effective Discipline for Children from 2-12.**

Dr Phelan seriously took us on a tour of teenagers, their normal behaviours, their ADHD behaviours and tips on how to handle them. All of his talks are delivered in a relaxed and fun style, which makes him a pleasure to listen to and you get a true feeling of his understanding of what you're going through because he has lived, it not just theorised about it. His adolescent range extends from 11 to 23. He says we should use the 30% Rule which means that you take the age of an ADHD child and subtract 30% to get



their true behavioural and emotional age. So someone of 16 will function at around just over 11 years old. Someone of 18 is about 13. It really helps to bear this in mind when you have expectations of your own children, although he also says we tend not to allow our kids to do what they believe they can do.

Dr Phelan thinks that Emotional Over-arousal should be a listed symptom of ADHD in the DSM IV Criteria as this one aspect causes most of the problems. He listed some of the normal teenager's behaviours and mentioned that they are all changing rapidly at this point in their lives, biologically, physically and emotionally. They become increasingly weird in our eyes, go in for piercings etc, and replace us with their peers. They become idealists, know-it-alls and self-conscious. Dr Phelan says that if you meet an ADHD teenager first thing in the morning don't make eye contact, walk swiftly by and grunt! Apparently this will all mean something to them!! He says don't let MBA's (Minor But Aggravating Problems) get you going. Have negotiated rules about phone use, messy rooms (stay out of them if it upsets you), appearance (let them present themselves in their own way) music (no generation ever liked the next generation's music – its traditional) Diet (allow them to decide where, when and what they eat). Control less. Don't feel you have to say something when you're angry or annoyed – cool down first. Things you should interfere in include things like Anxiety, Depression, Conduct Disorder, Driving, and Substance Abuse etc. Check out yourself too. If you're depressed this will affect how you deal with your kids He also gave us 4 Don'ts. 1. Don't Argue – it always takes two to argue just walk away from it. 2. Don't Nag –Repetitive verbal and often hostile comments do not work. If you ask them to clean their room 30 times and they still don't do it, *you* are the one with a problem! 3. Don't Lecture – The 'we never did this when I was a kid' routine doesn't work either. 4. Don't issue spontaneous requests or spontaneously decide to discuss a problem. Kids don't like things to be sprung on them! Make an appointment or have a family conference. The Things To Do List included: 1. Active Listening – actually take the time to really listen. 2. Don't Question them, talk about yourself, tell them what you went through. 3. Have Shared Fun – do some fun things together. 4. Use Positive Reinforcement or Praise. Some teenagers like really gushy praise while others prefer a business-like pat on the back. *But Do it.* He describes ADHD as the Garlic Disorder because it doesn't bother the person with it but it sure bothers everyone else!! If you ever have a chance to listen to Thomas Phelan live or on video do it – you will feel elevated by him.

## Passages of Adult ADHD: A Lifelong Journey – Michelle Novotni, President of the National Board for ADDA in the USA

Michelle gave us insights into the world of the ADHD adult and said many of them only recognise it in themselves when their children are diagnosed. The hyperactive element tends to go away as you age but becomes an internalised restlessness. Impulsivity and inattention remain quite strong into adulthood. Some ADHD adults use very strict structures to compensate for their ADHD. Many though suffer from: a disorganised lifestyle, forgetfulness, time management problems, impulsive spending, a chronic pattern of underachievement, patterns of periodic depression, difficulty controlling anger, a tendency to take on too many projects, interrupting of others, relying on others to organise them, speaking without consideration. On the strengths side she said that ADHD adults often had a wider overview than the rest of us and multiple intelligences. Ideas for helping adults with ADHD included: Counselling, Life coaching, Visualisation techniques, minimizing interruptions while they are trying to do something, ensuring that they have extra sets of keys, that regularly used items are kept in the same place and so on. She also said that next year two drug companies in the USA are hoping to bring out medications for adults with ADHD.

## ADHD Secrets of Success- Using NLP and other Tools to Create Powerful Transformation. Thom Hartmann

Thom Hartmann talked a lot about NLP- Neuro Linguistic Programming – which was developed 30 years ago. He discussed how our brains are wired to receive information in story form and that the brain can only track information for plus or minus 7 minutes at a time. He told us about how a therapist worked with a boy who wet the bed, by establishing a rapport with the boy by mimicking his behaviour, acknowledging it and then validating it and hoping for a change. Thom also talked about people's predicate language or the method by which they best communicate. Some people connect visually and this shows in their speech as in 'Oh I see', or 'See you later'; some are auditory with 'I hear you', 'Great hearing from you'; others are kinaesthetic, 'That's a good solid idea', or 'Catch you later'. If you drop into their language mode you can more easily connect. We took part in a role-play about 'Time Lines' but I wasn't able to feel the appropriate response and always feel silly in role-plays anyway!



Thom Hartmann

## DAY 3

*I crawled out of bed and struggled to get going for Day 3. This conference is always interesting and revitalizing but exhausting – or is my age showing! It was announced that the next ADDISS Conference is likely to be in March 2004 and possibly in Manchester.*

## What isn't ADHD although it looks remarkably like it!

**Professor Peter Hill, Child and Adolescent Psychiatrist at Great Ormond Street Hospital.**

Professor Hill runs a Tertiary level clinic advising Consultant Psychiatrists and Paediatricians about difficult cases. His caseload is solely from physicians and he is also working with the Tourette's Clinic.

He discussed the last 100 referrals he had received at his clinic. Of the 100, 14 turned out to be straightforward ADHD cases, 37 ADHD with Co-morbid disorders and 49 apparent ADHD cases.

Of the 49 cases: 10 were proven to be Autistic Spectrum Disorders, 8 were Anxious and two of these had Post Traumatic Stress Disorder, 5 were adopted from the Balkans, 4 had Global Learning Disabilities, 4 had Conduct Disorder on its own, 3 had Tourette's Syndrome, 3 had Language Disorders, 3 had Sleep disturbances, 2 had impaired auditory memory, 2 had Kleine-Levin Syndrome, 2 had Foetal Alcohol Syndrome, 2 had Low birth weight i.e. 1.5kgs and 1 had a Frontal Lobe Infarct. This was an intelligent and interesting talk with full explanations given about all the other non-ADHD problems.



**Realistic Hope for Individuals and Families with ADHD – Dr Thomas E Brown, Assistant Clinical Professor of Psychiatry, Yale University School of Medicine and Associate Director of the Yale Clinic for Attention and Related Disorders.**

I must admit to not really following much of what Dr Brown said. He had a lovely deep melodic voice and the words just wafted around over my head somewhere. It could have been battle fatigue at that stage! He did mention that the biggest problem facing those with ADHD and their families is ignorance, fear and prejudice, which prevent both children and adults getting the treatment they deserve.

**Developing Assessment and Treatment Programmes for Women with ADHD – Dr Patricia Quinn, Developmental Paediatrician and Director of the National Centre for Gender Issues and ADHD.**

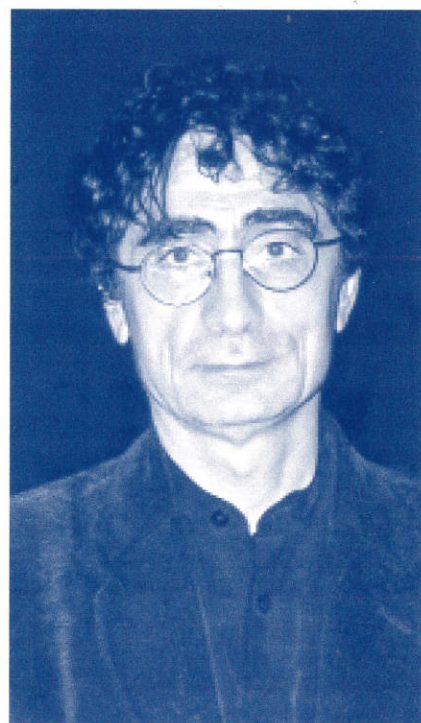
Wasn't sure what to expect from Dr Quinn's talk but from the moment I sat down was struck by her energy and clarity of thought. She discussed how ADHD women are often misdiagnosed with Depression, Anxiety Disorder, Bi-polar Disorder or Borderline Personality Disorder. Women with the predominantly Inattentive Type of ADHD are frequently overlooked and not diagnosed. Women with ADHD are more frequently overwhelmed by everything, which leads them to Depression, they seldom get enough sleep and are often embarrassed at having ADHD. Men with ADHD are told to get themselves a support system; women are the support system! Admin and being a PA are the worst jobs for women with ADHD. Household tasks often overwhelm them too. Dr Quinn told us of a group of women she worked with who set up a Laundry Support Network where they would all gather at one house with their washing and spend the day together while going through the washing. She discussed the relationships between Bi Polar Disorder and ADHD, as 20 to 25% of women with Bi Polar will also be ADHD. Shared features of the Disorders are: mood instability, bursts of restlessness, talkative, racing thoughts, impulsive and impatient,

impaired judgement, irritability, chronic course, lifelong impairment, strong genetic clustering.

Unlike ADHD Bi Polar Disorder is episodic and the mood shifts can take hours and days to change. Dr Quinn told us that the brain is a target organ for oestrogen, which has a profound effect on mood, mental states and memory. Whenever oestrogen falls below a minimum level required by the brain you get PMS. Women with Low Oestrogen levels, as in pre-menstrual, post partum, peri-menopausal or menopausal share several symptoms of ADHD such as: depression, sleep disturbance, irritability, anxiety, panic, memory deficits, cognitive dysfunction. Dr Quinn told us she was ADHD herself and thrived on medication. Many of the packed audience were medical professionals and a long and interesting question and answer session followed her talk. Excellent!

**The Defiant Ones – Dr Gabor Mate – Psychotherapist/Physician specialising in ADHD**

Another ADHD adult, Dr Mate was projecting a force field of energy that hit you as soon as you entered the room! His talk on Oppositionality gave me food for thought. For instance kids don't oppose you when you're not there! (Good – does that mean we can hide?) He also said that kids can't learn from negative experiences so we must. When kids are being oppositional it's not will but an automatic push back. The weaker your sense of self is the stronger your oppositionality will be. Gabor told us about how the terrible 2's is a natural part of development during which a child's own personality and will develop. He then stated that he disagreed with Dr Phelan's 123 Magic. As well as liking Dr Phelan I also liked his method and had used 123 Magic to good effect so felt a bit oppositional to Dr Mate at that point. He also talked a lot about Contra-will but I feel I'd have to read his book before I get a handle on that. His book is called *Scattered Minds*. Dr Mate believes that rewards are a form of coercion. The message given by rewards is that I want you to do this more than you want to do it. You are therefore using a reward to impose your will on someone else. He talked lengthily and fluently about



Dr Gabor Mate

oppositonality and says we shouldn't take it personally, it just happens automatically and we should expect it and make room for it. Parents should also take the time to teach their kids the words to use to enable them to explain their emotions. Certainly some of what he said left me feeling oppositional but it also left me thinking and you can't argue with that!

*The Conference ended with a Question and Answer Session with a panel from the speakers. Many Questions were asked and Answers given. Much praise was rightly given to Andrea Bilbow of ADDISS who had organised the Conference and gathered eminent and interesting speakers from all over the World to further raise our knowledge about ADHD and associated disorders. She also arranged a convivial meeting of all the Support Group representatives so that we could work more co-operatively. As a result, I am now in regular touch by email with a couple of other groups. I also feel 'topped up' again with knowledge and have the feeling of belonging to the beginnings of an International ADHD Army who will continue to battle for answers, solutions and treatments for all the lovely ADHD people we know.*

### Written by Judith Monk

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Tel: 01424 422105  
Fax: 01424 202933

### Additional Information

<a href="http://www.youngoptions.co.uk">www.youngoptions.co.uk</a>	Ron Weinstein
<a href="http://www.addcentre.co.uk">www.addcentre.co.uk</a>	
<a href="http://www.advance.com">www.advance.com</a>	
<a href="http://www.ncgiadd.org">www.ncgiadd.org</a>	Patricia Quinn
<a href="mailto:advancecpq@aol.com">advancecpq@aol.com</a>	Patricia Quinn
Scattered Minds	Gabor Mate
123 Magic book and video	Thomas Phelan



## ADHD Genetic Research

Dr. Philip Asherson, Dr. Jonna Kuntsi and Prof. Eric Taylor

### Research News

The MRC Social Genetic and Developmental Psychiatry Research Centre was established in 1994 with the aim of encouraging collaborative research between investigators from different scientific backgrounds. The Centre is housed within the new SGDP Building that was opened in February 2003 and is based at the Institute of Psychiatry, part of King's College London.

### Social, Genetic and Developmental Psychiatry Developmental Theme

The Centre's main Developmental theme leads to research focused on childhood disorders because relatively little is known about them despite their public health importance. However, the developmental perspective involves more than studying children - it is an aetiological approach that investigates when and how disorders emerge and change during development. We believe that such research is essential to result eventually in interventions that prevent the onset of disorders rather than waiting to treat full-blown disorders. The

Centre's approach to development spans the life course. For example, of considerable current interest are adult outcomes of childhood disorders such as ADHD.

### Genes and ADHD

Progress towards identifying the genes involved in ADHD has proceeded rapidly over the last five years. Most interest has focused on genes involved in dopamine pathways in the brain, such as the dopamine transporter gene, which Ritalin and other stimulants bind to, and one of the dopamine receptors called the D4 receptor gene. Evidence for the involvement of both these genes is increasing, although we do not yet understand how exactly changes within these genes increase the risk for ADHD.

Other investigators have been looking for regions of the human genome that are shared between siblings (brothers and sisters) that both have ADHD - so called affected sibling pair studies. Two new studies from the US and Holland may lead to the identification of new genes. Both of these studies identify several regions of the genome that may

be linked to ADHD and also contain genes that influence reading disability and autism. This raises the possibility that

that some genes that influence risk for ADHD also influence other developmental disorders and traits.



## Future Events...

### October

WORCESTER

**Decrease Inappropriate Behaviours and Increase Learning in Individuals with ADHD, related disorders and those with Challenging Behaviours**

Speakers include:  
Ron and Sally Weinstein

Friday 17 October 2003  
9 - 5pm

Sixways Conference Centre  
Worcester Rugby Club

Cost £55  
Group members £25  
Parents, students and low income families £35  
Contact: Worcester ADHD Family Support Group on 01905 745556

### November

KILMARNOCK, SCOTLAND

**Fact or Fantasy  
Conference on Adolescents and Adults with ADHD**

3rd November 2003

Speakers Include:  
Dr Eleanor Kerr  
Dr Bill Brown  
Ian Nesbett, Educational Lawyer  
Careers Scotland  
Elaine McAllister, Psychotherapist  
Andrea Bilbow, ADDISS

Conference Chair  
George Irving, Chair of Ayrshire and Arran Health Board

Contact Ayrshire ADHD Support Group, Jo Hamilton, 01294 605544

**Future events to be confirmed**  
We are hoping to organise a day for Specialist ADHD Nurses. This event will take place in London in February 2004. If you are an ADHD Nurse please contact ADDISS and we will forward information to you as soon as the date has been confirmed.

## The IMAGE Project

We are very pleased to announce the launch of a major International study called the International Multi-centre ADHD Gene project - the IMAGE project. This new project is an extension of previous work initiated at the SGDP Centre, that brings clinical investigators and molecular geneticists together from across Europe. The National Institute of Health, which is the main funding body in the United States, has provided around \$10 million for this research. This makes IMAGE one of the largest research initiatives on ADHD funded anywhere in the world to date.



# What is the IMAGE Project?

The IMAGE Project will gather medical information and DNA from individuals who have ADHD as well as from their brothers, sisters and parents.

The idea of this project is to create a resource that can be used both now and in the future to find the genes that cause ADHD. This is an exciting opportunity since the resource will be available to some of the best scientists in the world who want to find the genes involved. The first phase of this project will take five years during which DNA and clinical data will be gathered from 2,000 school age children with ADHD as well as their brothers, sisters and parents. At the same time we will begin to search the human genome - the entire set of human genes - for genes that are linked to ADHD.

## Who can take part in the IMAGE project?

To take part in the study your family should consist of two or more children, one of whom has been diagnosed with ADHD. Because this is a family study we will be looking at similarities and differences between siblings. We will be looking for genes that are shared by siblings who both have ADHD. We will also look for genes that are not shared by siblings where one has ADHD and the other does not.

## Linking ADHD, genes and cognitive processes

On specific psychological tests children with ADHD tend to have difficulties inhibiting inappropriate responses and sustaining attention over time. However, when the same tasks are made faster or more rewarding, their performance can improve drastically. By bringing together genetic approaches with research on psychological processes we hope to make links between genes, ADHD and problems in maintaining optimal states of arousal and attention.

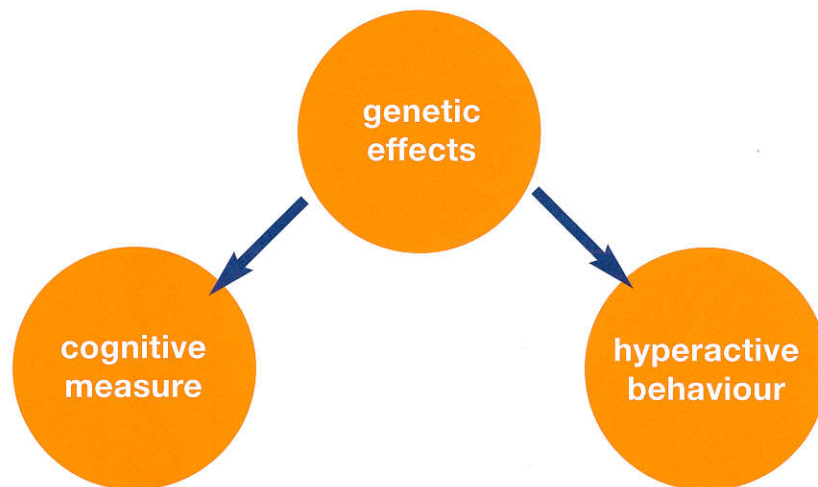
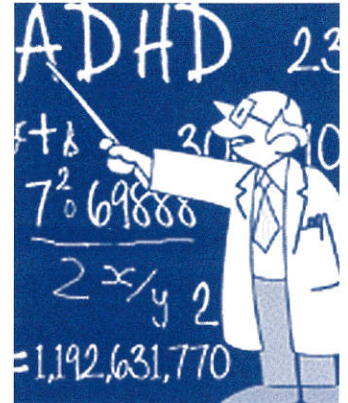
We will compare the performance of children with ADHD and their nearest-age siblings on a detailed psychological test battery. Comparing siblings allows us to estimate the size of genetic influences and investigate the contribution of specific genes to ADHD and performance on the psychological tests.

## Why find genes?

ADHD, hyperactivity and related problems are very common, affecting the lives of many children and adults. The disorder is recognised as one of the most

important cause of problems that some children have with their schoolwork and relationships with friends and family. These problems often have long-term consequences so that about two thirds of children diagnosed with ADHD have persistent problems that affect them as adults. By investigating the causes and finding out much more about how

genes and environments – nature and nurture – combine together to bring about ADHD, we will be in a far better position to develop the best and most effective approaches to help individuals with ADHD. Finding the genes involved in an important step in this direction since we know that genetic influences on ADHD are particularly important.



If you wish to take part in the IMAGE Project or want more information call our Freephone number:

Free phone number: 0800 123456

E-mail: [t.fay@iop.kcl.ac.uk](mailto:t.fay@iop.kcl.ac.uk)

Post: IMAGE Project, SGDP Building, Institute of Psychiatry, London, SE5 8AF



## The Sixth International ADDISS Conference

15-17th March 2004

Adelphi Hotel, Liverpool

### CALL FOR PAPERS

Working Title  
ADHD: Getting it  
Right in Europe

*The conference  
themes will be*

### Working Together

Paediatric and Child  
Mental health  
Education  
Youth Justice  
The Media

### European Solutions

Looking at good practice  
across Europe

### Research

### Management

As usual we will also be  
looking for presentations  
which help parents to  
manage and support  
their children.

The ADDISS  
Conferences are very  
much solution focused  
and we therefore  
welcome both parents  
and professionals to  
attend.

### Abstracts/ Proposals

Your abstract should  
be roughly 250 words.  
Please send it either  
by email to  
conf2004@addiss.co.uk  
or by mail to

Conference Committee  
The ADDISS Resource  
Centre  
10 Station Road  
Mill Hill  
London  
NW7 2JU

Closing date  
October 31st 2003



## Mental Health Workshops & Conferences

www.mole-conferences.com

- ☐ **Meeting the Mental Health Needs of Children & Young People with Learning Disabilities who have Mental Health Problems: Strategies & Frameworks**  
20th May 2003 **1 day conference**
- ☐ **CBT & Working with Anxiety**  
Tutor: Gladeana McMahon  
28th May 2003 **1 day Workshop**
- ☐ **Using CBT to treat Chronic Fatigue Syndrome**  
Tutor: Trudie Chalder  
9th June 2003 **1 day Workshop**
- ☐ **CBT and Trauma Related Guilt**  
Tutor: Stephen Regel  
16th June 2003 **1 day workshop**
- ☐ **Living with Asperger's Syndrome and High Functioning Autism: the family, the classroom, the workplace**  
20th June 2003 **1 day conference**
- ☐ **Working with traumatised children & families - effective interventions**  
Tutor: David Trickey  
23rd June 2003 **1 day workshop**
- ☐ **Supervision and Self Harm**  
Tutors: Chris Scanlon & Diana Menzies  
10th July 2003 **1 day workshop**
- ☐ **Caring, Child Abuse & Medicine - understanding what happens when doctors & parents disagree**  
*A one-day conference for all General Practitioners, Mental Health Professionals, Learning Disability, Child Health, Child Care and Child Protection Professionals*  
7th July 2003 **1 day conference**
- ☐ **An Introduction to Cognitive Behavioural Therapy**  
Tutor: Gladeana McMahon  
10th & 11th November 2003 **2 day workshop**  
*You will need to have attended either one of these Mole introduction to CBT courses, or a similar course, before attending the one-day specialist CBT courses run by Mole.*

All events take place in London  
Each day provides 5 CPD hours



**Fax**

**01273 242 634**

**01273 235 095**

**Email** info@mole-conferences.com  
**Web site and on-line booking**



# The ADDISS Affiliation Programme

**On the 10th and 11th May this year 24 Support groups were invited to come together in Birmingham to discuss a programme of Affiliation to ADDISS.**



After several months of discussion between ADDISS, the groups and a substantial number of Health Professionals, the meeting was arranged. The support groups across England, Wales, Ireland and Scotland have for many years worked closely with ADDISS in helping to support families, raise awareness and run conferences. It was felt a more formal partnership should be initiated, for several reasons. The most important being the need to ensure that families were receiving the same level of support and the same standard of support from all groups. The groups felt that through this programme information can be filtered up through ADDISS to the various Government Departments and to be heard as one voice and likewise information can be filtered down through ADDISS to all the groups.

Once affiliated to ADDISS, group leaders will receive regular training and on going support from ADDISS. Groups will be able to share areas of expertise with each other and to collaborate on national projects and campaigns. They will also have the backing and support of the ADDISS Professional Board.

At this first meeting groups received presentations from Professor Eric Taylor and Dr Nikos Myttas. They were able to ask many questions and have a healthy discussion. There was also a presentation on Dealing with the Media, by journalist Scarlett McGuire. In the light of the recent spate of articles in the media this presentation came at a timely moment. In return Professor Taylor was treated to a presentation by all the groups who each in turn gave an overview of their group and the activities and achievements experienced by those groups.

This first meeting and training weekend was attended by

The Bristol ADHD Support Group, The Ayrshire ADHD Support Group, The Sussex ADHD Support Group, ADDERS.Org/Thanet Adders, Dorset ADHD Support Group, ADD Together (Bournemouth and Poole), South Godstone, Gateshead ADHD, West Yorkshire ADHD, The Bay ADDLink, ADHD NorthWest, Lincoln ADHD, Suffolk ADHD, Malvern, West Glamorgan and West Wales, Milton Keynes, Leeds, Liverpool ADHD Project, Hounslow.

The following groups sent apologies but still wished to be considered for Affiliation. ADD+UP, Northern Ireland, Heart of England, Inverness and St Albans

Since this event several members of the above groups have come to London to spend time in the ADDISS Resource Centre. Many more groups have requested affiliation to ADDISS. It is hoped that by affiliating, we will be able to help and support groups through the hardships of keeping a group running. Affiliated groups will help to encourage, nurture and support new groups which are setting up.



Below are some of the comments made by groups when asked why they think they should affiliate to and work together with ADDISS

***'Our group is young and energetic and we need guidance. ADDISS provides the professional support we need to survive.'***

***'We hope to benefit from ADDISS's reputation and expertise and gain support from ADDISS and the other support groups and to set a standard for information shared'***

***To share information and support and to have professional backing. We feel that ADHD needs a national voice and would like this done through ADDISS'***

***'Our project is supported by professionals in health, education and social services and works in partnership with parents and children. We use evidence based practice and need to work with ADDISS to ensure consistency of approach. We hope to contribute to best practice in ADHD.'***

***'Affiliation to ADDISS is necessary to provide a unity for Support Groups allowing them to move forward as an informed and unified group with a powerful voice, to better the lives of all around ADHD'***

***'All local support groups need one umbrella organisation that they can come together under and have one strong voice, an organisation where you can get help, advice, training and have seminars/conferences where everybody can come together and share experiences and learn. We believe ADDISS could be that umbrella organisation that we connect to giving us one strong voice.'***

***'We feel that to run a group effectively and efficiently we need to be linked to ADDISS- to enable us to do more than give an opinion, but to give accurate statistics and facts - not fiction. - To avoid misleading members and to provide them with accurate and evidence based information. - To provide a national approach rather than a local approach - To stand together on issues to create better awareness and understanding. - To provide support to group leaders to head the group.'***



**If you would like your group to Affiliate to ADDISS, please contact us so you can be invited to the next Affiliation meeting.**



## Have you booked for Southport?

If you are intending going to the Southport Convention in September, we strongly suggest you secure your accommodation as soon as possible. This can be done by telephoning the Accommodation booking line.



**ONE CALL**  
SOUTHPORT ACCOMMODATION BOOKING SERVICE  
**0151 934 2432**

To book a place on the convention please send a payment of £30 made payable to ADDISS, together with your name, address and phone number.

If you are coming from either Essex (Hornchurch) London (Mill Hill) or Milton Keynes there is a coach running from these points to Southport at a cost of £15 return. This can be included with your payment.

Please send payment to:

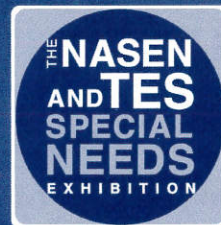
10 Station Road, Mill Hill, London NW7 2JU

## SUBSCRIBE TO ADDISS

and receive this newsletter, our catalogue of books and videos and regular updates on training courses, new resources etc.  
Please telephone for an application form.

**020 8906 9068**

Something **special** is happening...



**Dedicated exclusively to Special Educational Needs**

**The Business Design Centre, Islington, London**

Thursday, 30 October 9.30am-5.00pm

Friday, 31 October 9.30am-5.00pm

Saturday, 1 November 10.00am-4.00pm

Academic and commercial worlds will come together at The Business Design Centre in London to offer you information, inspiration and motivation. There will be over 40 seminar sessions to choose from, all prepared by NASEN. In addition, more than 150 educational suppliers, including some of the leading names in special needs technology, will offer you the opportunity to compare and purchase resources and services and discuss individual pupil requirements - making it a most rewarding professional development day.

Complete and return the registration form below to receive your FREE entrance ticket and copy of the seminar programme. Alternatively register on-line at [www.specialneedsexhibition.co.uk](http://www.specialneedsexhibition.co.uk) or call our ticket hotline on 01923 690620.

Remember - this is the only dedicated special needs event to be held in London this year organised and supported by The National Association for Special Educational Needs and The TES.

ORGANISED BY

**NASEN**

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SPECIAL NEEDS IT



How IT Works

### Registration Form We regret no entry to students under 18.

**For FREE entry please complete your details:**

Miss/Ms/Mrs/Mr First name

Surname

Job Title:

Type of establishment: Nursery/Pre School ☐ Primary School ☐ Secondary School ☐ Special School ☐

FE/Technical/Sixth Form ☐ Teacher Training College ☐ Local Authority ☐ Education Trade/Industry ☐  
(Please select as appropriate)

Establishment Name:

Establishment Address:

Postcode:

Tel Number (in case of query):

E-mail:

Mobile phone number and provider:

Data Protection: We may make names and addresses available to carefully vetted companies which may be of interest to you. If you would prefer not to receive such mailings please tick this box ☐

Please fax your completed form to 01923 690680 or send to:  
The NASEN & TES Special Needs Exhibition, c/o Expo-Systems Ltd., Park House,  
Greenhill Crescent, Watford Business Park, Watford, Herts WD1 8QU.

[www.specialneedsexhibition.co.uk](http://www.specialneedsexhibition.co.uk)

Code: 004

Have you read a book or seen a video that you would like to share with other parents and professionals? Please send your reviews to ADHD News.