

ADDISS

2 0 0 5 C O N F E R E N C E

at the Royal National Hotel, London

'Quality Matters' Sharing Good Practice

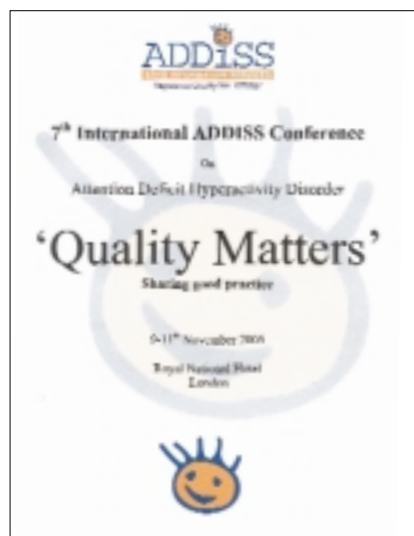
9-11th November 2005

As my much loved ADHD son matures and at 26, now manages his own life, the sheer demanding, punishing physicality of raising these children to adulthood begins to fade and at last relaxation has its place once more. For me each new ADDISS Conference always firmly revives the constant adrenalin rush of 'ADHD' life, with early starts, minimal short breaks, continuous input of information and the heightening of many emotions, raw and otherwise. At the end of Day 3 I return home exhausted but sated and more importantly afire with new information to pass on and a renewed desire to inform and protect those mothers still struggling for help and understanding.

DAY 1

Day 1 opened with an address by ADDISS Patron, Lady Astor of Hever, who talked feelingly of her ADHD and Autistic daughters. She observed that the newly popularised ASBO's (Anti Social Behaviour Orders), much championed by the existing UK Government, actually worked against our ADHD children, whose often unruly behaviour has a biological cause, by the lack of differentiation between them and children who have been badly raised.

This thoughtful opening was followed by an enthusiastically received video presenta-



tion from the team that ran the UK's first ever ADHD Summer Camp, *Camp 2005*. As I watched I noticed that collectively, the ADHD children had extra bounce and energy and an uncontained 'joie de vivre' but they also had an open faced innocence that made me feel very protective of them. The Camp attendees made the video themselves showing the range of activities from creative to sport while encompassing fun, social gatherings and relaxation.

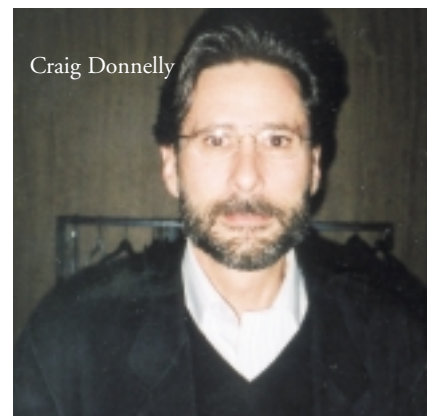
The Camp Goals were outlined as: Confidence, Achievement, Enthusiasm, Self worth and Fun. These were certainly evident in the film and bookings for next years Attention Seekers Camp 2006 are already flooding in.

The taking of 43 ADHD children to Legoland brought much applause for heroism and discovering what constitutes the science of *Grossology* brought much laughter and one or two groans of disgust! Trust me, you don't want to know! Next years dates are 30th July to 5th August and the website and contacts are listed at the end of the article.

The first impressive Keynote Speaker was Dr Craig Donnelly from the Dartmouth – Hitchcock Medical Center in New Hamp-

shire. He disclosed a number of relationships with large drug companies, which was understandable as he is an expert in psychopharmacology. He also has a vast understanding of ADHD and many of the co-morbidities which he then succinctly explained using nearly 100 slides. He first gave us a background to the use and development of the many drugs used to treat mental health problems and the timeline of development starting with Bensedrine in 1937 leading up to the creation of Methylphenidate in 1955 and Atomoxetine in 2003. Because of their length of use he told us that these older drugs were among the most tested and trusted.

Dr Donnelly then took us through the various Criteria explaining that ADHD was a chronic disease affecting pre-school, school years, adolescence and for some adulthood. The Worldwide prevalence from a variety of studies from many countries is between 5 and 8% with an Adult prevalence of 4% equivalent to 7 million adults. The 1999 Multimodal Treatment Study of children with ADHD pinpointed the percentages of comorbid disorders found along with ADHD giving 40% with Oppositional Defiance Disorder, 34% with Anxiety, 14% with Conduct Disorder, 11% with Tics and 4% with Mood disorders, 31% had ADHD



Craig Donnelly



Zara Harris

alone. He gave us startling illustrations of the cost of ADHD by using USA medical costs which show that ADHD children and adults cost 2 1/2 times more in medical fees than non ADHD and that ADHD children too are more than twice as likely to be arrested for crime during adolescence.

Dr Donnelly pointed out that families had the most contact with an ADHD person and that is where the treatment programme should begin, with parental behaviour management training, followed up with school based management, Social Skills training and perhaps Cognitive Behavioural Therapy for the person with ADHD to alleviate some of the symptoms of ADHD and any comorbid disorders. The best results are achieved when used in conjunction with appropriate medication.

Dr Donnelly discussed the medications used in treating ADHD backed by the biological information, which has been proven using genetic research, and PET scans of brain activity in ADHD and non ADHD brains.

This fulsome and thought provoking lecture was followed by Dr Paramala Santosh a Consultant Developmental Psychiatrist at Great Ormond Street Hospital. He had been tasked 20 months ago, with developing a specialist service, where medical practitioners could refer complex and difficult to diagnose cases with multiple disorders. Most of his referrals have at least 4 disorders. His feeling is that we should move away from specialist ADHD services, as uncomplicated ADHD should be able to be dealt with in primary care. ADHD when partnered by comorbid disorders is no longer ADHD and requires a clinic that can identify and treat a wide range of disorders. He is very interested in developing technology based diagnostic and treatment methods using video links and web based assessment processes. Dr Santosh's clinic only takes referrals from Psychiatrists and Paediatricians. The Cases are discussed by his multi disciplinary team and prioritised. They then undertake around 15 to 20 hours of investigative work before even seeing the child. Part of this is an online interactive pro-

gramme for the child to fill out which looked well prepared and engaging.



Steve Brown and Alistair Roy

Fintan O'Regan, the ADDISS Charitable Trust's Education Director relieved the tension of 4 hours intensive listening and learning by making us all laugh while delivering some important 'sound bites' on educating ADHD children. He recommended buying and reading Ross Greene's book *The Explosive Child*. I've already ordered it!

The afternoon of Day 1 then divided into parallel sessions and I opted to listen to an ADDISS Conference favourite, Dr Thomas Brown, telling us about Assessment & Treatment of Complicated ADHD. He likened an ADHD brain to a symphony orchestra with a duff conductor. The parts all work but the link that helps them function properly is not working well. This link is called Executive Function and it should Connect – Prioritise and Integrate Cognitive functions moment by moment. Dr Brown told us how EF capacity develops throughout childhood and adolescence and that demands on EF increase with age. This means it can often be difficult to diagnose ADHD before the age of 6 as required by the DSM 4 criteria. Using computers terminology he told us that ADHD is a problem of the brain's operating system not the software! He also stated that adults with ADHD have a 6 x greater risk of acquiring psychiatric disorders than non-sufferers. A frightening and expensive statistic.

My choice for the next session was Zara Harris a specialist Occupational Therapist who has worked extensively with people of all ages with ADHD. I was interested in what suggestions she might make. Zara broke down the many categories of difficulty found in ADHD and gave ideas on how to tackle these in the workplace. These can also work in a school or home setting too. Some were: Hyperactivity – exercise before after and during breaks; Inattention- use a timer or beeper to cue you, reward yourself when completing tasks, write any 'Aha' thoughts in a notebook rather than go off task. Hyperfocussing- use planning – do the boring stuff first, ensure regular stretching breaks and so on. She also recommends using post it notes in

bright colours and found Stephen Covey's book *The 7 Habits of Highly Effective People* recommendable.

DAY 2

The second day opened with a talk from Dr David Coghill and Andrea Bilbow about the NICE and European Guidelines. Dr Coghill did most of the talking! He described the differences in approach to diagnosis and treatment between current National Institute of Clinical Excellence (NICE) and European and American guidelines. The European for instance begin with a clinical interview, then observation of behaviour, obtain and analyse school and pre school information, psychometric assessment and physical assessment. The Americans say that screening for ADHD should be part of the assessment of any patient referred to mental health services and their Clinical Guidelines developed by the American Academy of Paediatrics are specific and detailed and include evaluating for co-morbid disorders. The UK's NICE guidelines needless to say are still in development but are predicted to suggest that medication cost will be a factor. Andrea made the salient point that while medication is important it must still fit in with the lifestyle of the child and family and should not be just about cost. Dr Coghill then talked about the different types of drug treatment available saying that there is evidence that Concerta is stronger than Stattera. He added that the biggest difference between the UK and the US is that here, Psychiatrists are far less likely to use multiple drugs combinations.

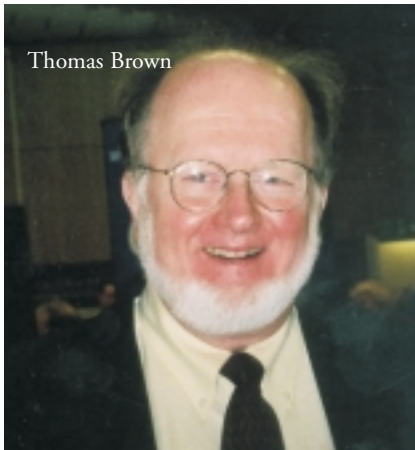
Dr Mary Solanto followed with a talk about a new psychosocial treatment that she has developed for treating adult ADHD centred on Time Management, Organisation and Planning. It is believed that in the US 4.3% of ADHD adults lost \$77 billion in reduced earnings as a result of Time Management, Organisation and Planning problems that cannot be remediated by medication. This was an in depth and interesting session about how Cognitive Behavioural Therapies can help these adults achieve a good measure of control of their lives. These are her CBT Mantras:

- If it's not in the planner it doesn't exist
- All things must be done in priority order
- If I'm having trouble getting started then the first step is too big (a small step is better than no step)
- Out of sight, out of mind (distraction control)
- Things you want to remember *Must be visible*

- A place for everything and everything in its place

To tell you a secret I've already started using her techniques myself and they work!

Dr Gabrielle Carson was the third of the keynote speakers and discussed *Issues in the diagnosis and treatment of ADHD and bipolar disorder in children*. She told us that the emotional elements of ADHD are not listed in the DSM4 Criteria for ADHD and in her



Thomas Brown

opinion they should be. Dr Carson gave us a detailed description of Bipolar disorder and said that 60% of teens diagnosed with Bipolar had comorbid ADHD. She then gave us detailed slides about the disorder, treatments and order of treatments.

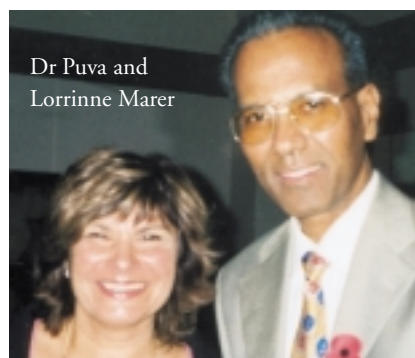
The final speaker of the morning was Dr Thomas Brown on *The Challenges of ADHD in Adolescence and Adulthood*. As always he gave clear insights into how ADHD travels on into adolescence and adulthood but with changes. The hyperactivity becomes a general restlessness, the impulsivity lessens but the major complication continues full strength and that is inattention. He says it's not inattention as in not being able to focus as when taking a photograph but inattention is a problem when driving a car because it requires continuous, complex interaction of the shifting and refocusing of attention and the use of working memory.

Dr Brown told us more about Executive Function. The structures and functions that support EF are not fully developed at birth but begin from around 2 to 4 years old and then continue to develop into the 20s. Dr Brown then used case studies to further illustrate problems of EF. He has an excellent website and a new book out too, both mentioned at the end of the article.

After lunch we were back into the realm of choices and I opted to listen to Dr Philip Asherson and his *Assessment and Treatment of Adults with ADHD*. I must confess to hoping he was really interesting because a good lunch and warm room can lead to eyelid droop!

His eye-opening start was a discussion

about the Image Project where families from many countries are taking part in a large-scale study for scientists to be able to try and map the genetic ADHD markers in the human genome. Find details of IMAGE at the end of the article. Dr Asherson told us that many ADHD adults are being wrongly diagnosed with a Personality Disorder as some symptoms overlap. He says the risks associated with adult ADHD are Anti Social Behaviour, alcohol and drug misuse, driving accidents, academic and employment problems, marital discord and parenting difficulties. Dr Asherson concluded by saying that Adult ADHD must be recognised because it is impairing and it can be treated and too many adults have been treated for other mental disorders when in fact they have adult ADHD.



Dr Puva and Lorraine Marer

My final choice for the day was to find out more about what a GPWsi was! Dr Gill Salmon, Consultant Child & Adolescent Psychiatrist from Swansea was there to tell us. It means *General Practitioner with Special Interest*. This is a new concept which it is hoped will allow some GPs to study ADHD and then be able to diagnose and manage children with ADHD in a primary care setting under a shared care arrangement rather than them languishing on a CAMHS waiting list. With increased awareness of ADHD comes more and more referrals to CAMHS and consequently longer waiting lists. This new development will allow some GPs to add this specialism to their portfolio and help relieve some of the pressures on CAMHS. Training is being made available through both paper and web based learning. I wasn't able to stay to the end of the talk as my 15 month old Granddaughter was rushed into hospital so like the 'helicopter' Mum I am, I rushed to smother both her and my daughter in love and support and just hover over them. You'll find the GPWsi learning website listed at the end.

DAY 3

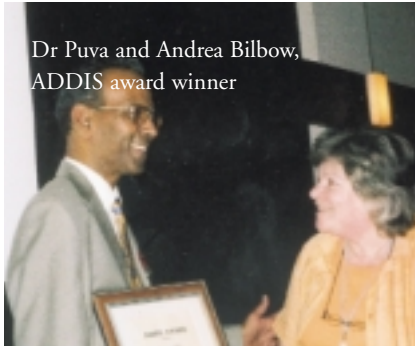
As I struggled to find some spare 'mind space' to add new information on Day

3, I realised that next up was a friend, Lorraine Marer, a behaviour specialist, who with Dr K Puvanendran, Consultant Paediatrician at Basildon Hospital, had been running a group training programme for parents/children with ADHD and for the siblings. Siblings are such a neglected group, frequently ignored and sidelined because of the huge attention required by an ADHD brother or sister, they can often feel lost. This Partnership involved, 6 evening workshops for parents, 4 sessions for ADHD children and 1 for siblings. The team received a Partnership Award 2005 from Basildon PCT. Dr Puva, as he's known talked eloquently about ADHD and his role in putting the partnership together. Lorraine is always good value as a speaker as she's cheeky, funny and dare I say hyperactive.

The second session I chose to listen in on was run by Dr Nikos Myttas, Consultant in Child and Adolescent Psychiatry at St Leonards Hospital London, who instructed us on the *Diagnosis and Treatment of ADHD in Girls and Young Women*. He explained that there has been a bias against diagnosis in girls and women due to the general use of male-specific diagnostic criteria. He then described the female specific clinical and treatment issues with an emphasis on the cardinal features that distinguish male from female forms. The Inattentive ADHD form is the variation most often found in girls followed by the Combined Type. Tellingly he was able to give us diagnosis ratios for Boys to Girls, which suggests 3:1 is average, but there is no statistical evidence for ratios in the adult population. Girls with ADHD are largely unrecognised by teachers, experience greater peer rejection, are inattentive rather than hyperactive and can seem sluggish or spacey. The girls tend to be less aggressive and are more able to hide externalising disorders and develop compensation strategies. The factors that often lead to late diagnosis are: a usually high IQ, obsessive symptoms, no associated specific learning difficulties, often good temperament, hard working and from a stable background. Dr Myttas gave a clear understanding of the differences in and difficulties in treating girls compared to boys too in that girls must have their premenstrual symptoms



Nikos Myttas



Dr Puva and Andrea Bilbow,
ADDISS award winner

addressed and any possible pregnancy can interfere with medication regimes. An interesting and instructive talk.

After a quick coffee the final session of the morning loomed and I wondered just how much more I could take in... I chose to hear about *ADHD and Substance misuse and treatment with a European Overview*. One of the presenters was another old friend, Lancashire policeman Sergeant Steve Brown who with his colleague Inspector Phil Anderton has between them created a vast information network on ADHD not only in their area but nationwide. Today, however, Steve was partnered by Alistair Roy a Senior Lecturer from The University of Central Lancashire (UCLan) who gave us a detailed talk about the connections between untreated ADHD and crime, anti social behaviour and drug abuse. Lancashire Constabulary and the Lancashire Drug Action Team have established a working group to explore the issues. This Study offers a critical review of the debates around ADHD and its relationship to substance abuse and any interventions and also examines three projects known to be treating ADHD and Substance Abuse simultaneously. These clinics are The Bergen Clinics in Norway, The Trimbos Institute in the Netherlands and the Adolescent Health Centre in the USA. Alistair Roy then outlined the programmes currently being run and made a suggestion for a UK pilot programme that would be: Multimodal, structured for ADHD, have long term structured aftercare and be based on UK research. My brain is definitely made of an elastic compound because just when I thought it was full it stretched some more. An excellent presentation.

After a final lunch with the many friends I made at the conference Andrea delivered the name of this year's ADDISS Award winner. It was a deserving Dr Puvanendran of Basildon Hospital in Essex who was described as having compassion, dedication and professionalism in improving the lives of children, adults and families who daily struggle with ADHD.

The Conference closed with a talk from another Conference favourite Australian Professor Loretta Giorcelli who discussed Parenting Modern Children and Teens. Most of the lecture was about disability in children and how this can impact on families. Loretta is a charismatic speaker and opened by telling us about Emily Kingsley, the mother of a Down's Syndrome son and the way she explained her acceptance of her fate. The story begins, I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It goes like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans; the Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may

never be free to enjoy the very special, the very lovely things... about Holland.

Having been taken to Holland myself along with many other mothers in the room, we knew exactly what she meant and the tears came. As always ADDISS delivered up another life-changing conference, a chance to imbibe support and knowledge, make and renew friendships and importantly gather contacts that can help ensure that ADHD is recognised and most importantly properly screened for and appropriately treated using whatever it takes by way of resources and facilities. **Judith Monk ADHD Adult & Adolescent Support Network jmonk45582@aol.com**

A list of various contact points follows:

Who can take part in the IMAGE project?

They are looking for families with one or more children who have ADHD and are currently attending school in the United Kingdom. To take part in the study your family must consist of at least two children, one of who has been diagnosed with ADHD. They are looking for genes that are shared by siblings who both have ADHD and genes that are not shared by siblings where one has ADHD and the other does not.

Contact Details

The IMAGE Project, The SGDP Centre, Memory Lane, Institute of Psychiatry P080, De Crespigny Park, London SE5 8AF
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E-mail: IMAGE@iop.kcl.ac.uk
Dr Asherson p.asherson@iop.kcl.ac.uk

www.DrThomasEBrown.com

Attention Deficit Disorder: The Unfocused Mind in Children and Adults

by Thomas E Brown, PhD. £14.95 from amazon.co.uk

New Haven, CT: Yale University Press, September 2005

Dr Gill Salmon, Consultant Child and Adolescent Psychiatrist, Swansea.
www.adhtraining.co.uk

Professor Loretta Giorcelli
www.doctorg.org

Attention Seekers Camp
www.attentionseekers.org