

JONATHAN TOMMEY REPORTS

MORE Testing Times AHEAD

As the father of our wonderful son Billy, I have, over his first three and a half years of life, become disappointed, disillusioned and unconfident of the 'professionals' looking after his medical, educational and psychological welfare. Since 'Billy's Story' was aired on the *Tonight with Trevor Macdonald* programme on ITV this year we have been inundated with your stories, questions and concerns about your children and the difficulties not only you have found raising an autistic child but also in trying to find out what resources are available to best help you and your child.

THE SHEER DESPERATION WE FELT WAS INTOLERABLE

Recalling Billy's initial diagnosis and the great pain in trying to accept it still brings back very sad memories and emotions, feelings that only those associated with our dilemma can understand. We would read stories and reports of autism and how very black the picture was painted; no cure; no hope; institutionalised; no friends or companions; hardly any could grow up to lead a 'typical' existence; self destructive; epileptic and the like. The sheer desperation we felt was intolerable and the sympathetic support, help and information we so much needed was totally lacking. We simply had no alternative but to progress with Billy's future as best we could! Giving our child the best possible opportunities in life was our shared belief with love, support, enthusiasm and encouragement. We heard of Victoria Beck's chance discovery of the hormone 'secretin' and thanks

to my father for acquiring it and Dr David O'Connell administering it, we have found a tremendous improvement in Billy's concentration, alertness, interaction and sociability, eye contact and his improved bowel movements. This has been truly wonderful, *but* it hasn't cured him. We are therefore still looking for greater success with the aim that Billy will go through life a happy, typical human being who will be

able to interact, play and communicate with whoever he chooses. I am encouraged to see a great deal of effort going on into autism research and support and thanks must go to Paul Shattock, Dr Bernard Rimland and associates, Dr Paul Reichelt, Rosemary Waring, Dr Andrew Wakefield, to name but a few. As a parent of an autistic child I need to find as much information as I possibly can and evaluate it to make decisions as to the best possible way forward for Billy. This will involve medical testing, educational requirements, domestic intervention and the like to try and resolve his problems in the most effective way and in the shortest possible time. Of course we need to work with researchers and professionals but as importantly we need to work with the parents of autistic children and indeed the children themselves!

SO WHERE DOES THIS ALL LEAD?



Jonathan and Billy

Following numerous discussions and meetings with The Priory Hospital, Roehampton, a decision was made on Tuesday 14 September 1999 that they were not prepared to host the Autism Treatment Centre. This was primarily due to problems that could have arisen with the Ethics committee because of the testing and research programme that we were hoping to start. Of course, they have their reputation to protect and I for one would not want them to jeopardise that. I am obviously extremely disappointed with their decision and like many others I feel very let down. But I will not give in and I have already started negotiations to find a more structured team and practice to host the centre. The treatment and diagnostic testing for children placed on the autistic spectrum will happen! I have a personal theory for what I believe has caused 'autistic traits' within my lovely son Billy. I firmly believe that he wasn't genetically born autistic but for him it is an acquired



Billy

condition. A condition that can, I believe, be treated and reversed.

However, before I jump to any conclusion it is apparent to me that there is just not enough diagnostic testing made available for our children.

Without the knowledge obtained from such diagnostic testing of autistic children's problems how can doctors, paediatricians and the like tell us what the best form of treatment should be?

I am currently investigating the possible tests that I want to conduct on urine, hair, stool and blood samples from Billy.

This will then present me with a clearer picture of his present state of health.

I am researching tests to look at his immune system, food allergies and immune dysfunction. Organic acid tests for levels of candida and fungal infection, liver function, trace elements and metals, vitamin, mineral and amino acid analysis. Also, intestinal permeability, faecal secretory IgA and parasite assessment.

Once these results have been obtained I shall look to correct them simultaneously with the hope of restoring his 'whole' homeostatic balance, therefore allowing for normal functioning of his organs, tissues and cells. It is clearly a complex issue but until the jigsaw is broken down piece by piece then fitted back together what hope is there of forming the whole picture?

With these results I may be able to answer some of my more probing questions.

In Billy's case:

- Why has he had bowel problems?
- Why has he swollen lymph nodes?
- Why does his urine smell strong?
- Has he a lowered immune system?
- Has he a candida, fungal gut overgrowth?
- If his gut is leaky – then why?
- Why was mucous, like albumin present in his stomach?
- Is his gut pH correct?
- Has he the correct nutritional values?
- Has he active viruses within the gut?
- Has he got gut parasites?
- Why did he get so many chest infections and glue ear?
- Are the foodstuffs he eats digested properly?
- What foods is he allergic or intolerant to?
- If he has long chain peptides in his urine – why?
- Has he high mercury readings in his tissues?
- Has he reduced oxygenation to certain areas of the brain?

WHY? WHY? WHY? WHY? WHY?

These are but some of the questions to which I need answers. The correct diagnostic testing for gastrointestinal problems, for nutritional, immunological and metabolic problems along with endocrinological functioning testing, will provide these answers.

Once we have conclusive results then we can start to address each issue which is why a centre for testing and treatment is essential. We shall aim to work in association with the world's top researchers and specialists. I hope we will be able to ask for their help, knowledge, guidance and support for we need to work together. No one individual will know the answers to all our findings. Watch this space! In the next issue of the *Autism File*, I shall be reporting on the DAN (Defeat Autism Now) Conference with the latest strategies and theories on autism from the world's leading professors, doctors and researchers. I'll update you on where we are with the Autism Treatment Centre, diagnostic testing, Billy's results, treatments and progress. We'll look at the links between suppressed immune systems and fungal overgrowth along with the catastrophic consequences that can occur. Is Autism merely a suppressed immune deficiency syndrome and if so what can be done to overcome it? When I leave Billy in this world I would like to think that I have done as much as I possibly could to help him achieve his true potential. When I have achieved this I shall be so very, very happy, knowing I have left a happy, healthy, able-bodied individual to truly survive as an independent in our multicomplex society!