Guide to Treatments for Autism and related disorders.

Come What May-A Comprehensive Guide to Traditional and Non-Traditional Treatments for the Autism Spectrum

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Foreword

Anyone who's coping with an autism diagnosis in their family is in need of accurate, sympathetic and reliable information on all the issues - practical, medical and emotional - in order to get access to the best support and treatment available. For families of newly diagnosed children it can be an almost impossible task to find this information, or to know where to ask for the help you need. Too often parents are given a diagnosis of autism for their child without an understanding of available treatments, therapies or support networks. This can be devastating to both their child's progress and their family's emotional well-being.

Speaking from experience I can say that most families go through several "phases" after their child is diagnosed within the autism spectrum. First there is denial. This may affect dads more than moms but sadly, until both parents (and the rest of their families) acknowledge that they have a serious problem on their hands, they are just spinning their wheels. Once the reality of autism has set in, there is the grieving phase. While you may feel completely consumed by grief in the beginning, it does get better. As a parent of an affected child, I can honestly say that I don't think you ever get completely through the grieving phase, but, given time and the very best emotional support, you do start to feel human again and able to face the issues at hand. The third phase typically experienced is one of anger. Hopefully this phase is short-lived although it never really leaves you. One of the most important things you can do for your child is become their advocate, and doing so with a small amount of fire in your belly, is essential! The final and most important phase is action. And this is where Ronna's book comes in…

Her book is about the practicalities of living with autism in your family. It provides clear, non-technical information about the kinds of autism treatments that may be suitable for your child. More importantly, Ronna addresses these issues in a series of short chapters perfectly written to introduce parents (and caregivers) to the vast array of traditional and non-traditional autism treatments available while still maintaining humor and hope in their lives. Recognizing that some of the rather bizarre behaviors exhibited by our children are sensory related is a great relief to parents, and she has a strong presence on each page, having been down this road herself.

In these pages, Ronna has written a book that not only informs and instructs, but also entertains! That is why I love it. I just wish this book had been available to me when my son was newly diagnosed with autism and we were given little hope for his future. Shortly after my son was diagnosed, I remember talking with another parent who had been down this road for several years. She was explaining the various sensory issues her son had. I politely listened and then after a while told her that my son didn't have any sensory issues. She just smiled. How wrong I was! I just didn't recognize them. Many of the suggestions for dealing with specific sensory issues that Ronna describes are things we do on a daily basis with our son. I just wish it hadn't taken us over a year to implement them. Be thankful that Ronna has brought them all together in this wonderful, easy to read guide to treatments.

I am honored to have been asked to write the Foreword for this book. Perhaps the essential compliment I can pay is that this book makes you want to sit down and read it from cover to cover.

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November 2005

Chapter 1 - Involuntary Entry into the World of A.S.D.

Or Diagnosis- Now What?

"Never knew, I could feel like this, like I've never seen the sky before......"

Good day. I hope you are well; but chances are if you have found this book all is not well in your life. Unless you are, of course, interested purely for professional reasons in the topic of this document. The words of the song above most likely describe the way most parents feel at the birth of their child.

Let me tell you from where this book has originated. I am the parent of a boy (my middle son) who has the diagnosis of PDD.Nos (for you laymen out there it is-Pervasive Developmental Disorder-Not otherwise Specified) in the D.S.M.-IV.

I began my involuntary orientation when my son was 2.5 years of age, and received the diagnosis from a local developmental pediatrician. I am also an Occupational Therapist, and had already been for seven years when my child was diagnosed. I was not, however, a pediatric therapist at that point in my career.

My task of writing this book is based solely on the wish to distribute as much information, as a guide, to as many in need of it as possible. I wish that when I had received my diagnosis that my book had existed, as I felt completely and utterly hopeless and alone. For six months my child underwent Early Intervention, as it is termed in our state. He had Occupational, Speech and Developmental Therapies, all from good therapists, but his progress was almost nil after 6 months. After I pulled myself out of my clinical depression, I was now angry.

What had happened to my child? He was normal. He met all developmental milestones till age two. He had 6 words, eye contact, crawled, walked, played and had appropriate affect. Then after a week long viral/bacterial? illness where he was febrile, he left us.

Let’s start at the beginning; always a good place, eh?

First off, who did your diagnosis? If it was a good doctor, he should have looked for the following tests directly after the first visit- we are talking a developmental pediatrician, here, not a DAN! Doctor-we will cover those further ahead.

Chromosome Karotype(any gross problems with the genes)(not ones still in research -for example chromosome 4, and the NAS-1 area, or CD-4), Inborn errors of metabolism (many- P.K.U. etc), EEG, sleep deprived, and anti-giadin test (same blood test used for celiac disease- to detect wheat allergy), Copper to Zinc Ratio, heavy metal testing. These are starters, and if your child has overt neurological signs, an MRI.

If this has not been done- ask. If they won't do it, change doctors; he is going to slow your recovery of your child down. I am astonished at the number of patients who come to my practice who were diagnosed by a PHD, and were never directed to an M.D.-essential in the road to recovery

Therapies have hopefully been prescribed- Behavioral Therapies- with a Therapeutic Staff Support and a Behavioral Specialist Consultant, up to 40 hours per week per Ivar Lovass' study, Occupational Therapy (only if it has a sensory integrative component-it is essential for these children) and of course Speech Therapy (preferably one who will let them move around a bit to stimulate their Vestibular System).

Now what? We wait.

No, we never wait.

We move on and read and learn till our heads feel as if they are ready to bust open, and they might, who knows? It will make a great new topic for Stephen King, I am sure.

Biologically there are many things going wrong with your child. I am going to go over as many as I have researched, and then it will be followed up with as many materials I have read. Assume I have read every research study or book mentioned here unless I specifically state I have not.

When you finally make that appointment with that specialist, there is usually a 4 month waiting period till you actually get some answers. I suggest you start with these three books,

Special Diets for Special Kids- by Lisa Lewis, P.H.D.

Unraveling the Mystery of P.D.D. and Autism -by Karyn Seroussi

Your Child with Special Needs- by Dr. Stanley Greenspan

These books will explain the diets to you, as well as outlining Dr. Greenspan’s approach, "Floortime," in trying to connect with your child’s seemingly random behaviors and play patterns. These are not random, but we need to learn how to be sensory detectives to decipher behaviors. Dr. Greenspan's book is a good resource to assist you at deciphering what level your child in functioning at and attempting to break into their world. Hopefully, by the end of this book, that will be accomplished.

What else can you do?

You can join a Yahoo group if you have internet access. When I started this helacious amount of information retrieval, I did not have it as yet. If you do not, go to the library and print out info you find there.

Yahoo Groups at the time of this writing that I have found helpful are;

Chelatingkids2

ABMD-Autism Biomedical Discussion Group

Autism Immune-purely for the research articles they disperse

Sulfer stories

These can give you a round the clock, round the globe connection to others in your situation, and usually very intelligent others, some physicians and researchers, who are knowledgeable in the biomedical approaches I encourage for your child.

What else can you do? If you were like I, my way of coping with the illness once I got over the initial shock and depression was to become obsessed with information gathering (all of my friends, especially my colleagues are sniggering at this, now and coughing under their breath, ”Asperger’s Syndrome”) as I was literally obsessed. My computer is filled with research articles from the past seven years gathering information to write this document. I will include some of them, but in fear of having this read like stereo instructions, I will choose them carefully.

Helpful Websites you can start with are;

Autism Research Institute- this one has a list of all of the practitioners in the US who are versed in the DAN! Protocol.

Autism Network for Dietary Intervention- A Network is compiled of people in your area who are willing to act as mentors to the diet, as well as a newsletter for you to join if you wish.

OOPs! Wrong Planet- this is a personal favorite of mine, it has thousands of web rings touching every aspect in the ASD world.

Generation Rescue- non profit organization with the purpose of dispersing information regarding heavy metal poisoning and its relationship to autism

Developmental Delay Resources

Autism Publishers:

Jessica Kingsley

Future Horizons

*About this time, probably, your head is beginning to spin with the load of information. Take heart, many of us have some before you, and you are not alone. When I heard about the diet 6 months after diagnosis, I cried. All I could think of was first all of the therapies, now this? But I was desperate. My child had no speech, had explosive behavior, could tantrum for up to a half an hour at a clip, and had previously had 6 words prior to regression. So, I decided I would keep a journal, and if at the end of three months, it had not helped, I would discontinue it.

At the end of three months, he had reached 600 words. Now don’t get all excited. Every child is different- I have seen children still acquire no speech from changing the diet, but maybe another area of development improves, such as decreased tactile defensiveness, or increased attention to task.

Each following chapter will be dedicated to issues we deal with this disorder, as well as more references to keep reading and learning. When you come across the * section, I will be sharing some of my own personal experiences, either with my own child, or one from my practice. I do not have the emotional fortitude to take you through the emotional journey of this (probably why I never went to a support group-save our biomedical one). My approach has always been pragmatic," Yes, it is horrific. Now what can we do about it?"

If you need some support emotionally, may I suggest?

Facing Autism- by Lynn Hamilton

Laughing and Loving with Autism- by Wayne Gilpin

Treating Autism: Parent Stories of Hope and Success- edited by Bernard Rimland and Stephen Edelson

Some of the things I share will be clinical observations, just my own perceptions (however, my patient's parents will attest that they work), and suggestions for remedying the situations.

The caveat is, of course: ***Nothing in this book should be taken as medical advice- this a reference book. Any procedure, either medical or therapy, requires the supervision of a licensed medical specialist.

Recent statistics are 1/150 boys are being diagnosed with some form of Asd. The number of children being diagnosed as having autism rose by 210% in California in an eleven year period, as per U.S. News and World report in 2000.

As I stated, you are not alone.

Take my hand, take a deep breath, and don't look back.

Shall we begin?.....................................

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