Family history review of a large consecutive group of diagnosed autists, ages 2-24 years

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Introduction

World Community Autism Program includes in its founding statements the stated aim of seeing autism redefined as a treatable condition. In 1994, Sara Johnson started a journey to recovery after initiating a new diet, which came to be known as 'Sara's Diet'. Between 1994 and 2002, several thousand individuals with autism followed the guidelines of Sara's Diet. Although many parents reported results varying from improvement to recovery, we were usually not in a position to verify these results.

After the phenomenal results gained by the daughter of a Medical Doctor, we were invited to meet 68 autists whose families wished to implement Sara's Diet, plus one whose consultation was provided through his physician. After providing a one-day seminar to lay out the principles of the dietary approach, we visited the families, mostly in their own home and provided detailed dietary recommendations to each family. Our only criteria for inclusion was a diagnosis of an Autism Spectrum Diagnosis – Autism, Asperger Syndrome or PDD-NOS. Some had used or were using a variety of other therapies, including GFCF diet, enzymes and supplements, Auditory Integration Therapy and Applied Behavioral Analysis.

The very nature of Sara's Diet requires that the recommendations are individually determined. There are many factors that we consider. These factors are, among others, medical history, physical signs and symptoms, history of development of autistic and other behaviors, family medical history, present diet, supplements and medications used, relationship to food and feeding, testing for food allergies and sensitivities and other testing as available. Pre-consultation testing was not required.

The only essential factors common to all diets is the total elimination of dietary lutein, artificial food dyes and Aspartame, and recommendations that aim to provide all known and suspected essential nutrients, preferably from foods but may be from supplements, taking into account that optimal nutrition is individual and varies particularly in the autism population. Other frequent elements of the diet might include: removal or reduction in intake of gluten, casein, soy protein, other carotene pigments, high purine foods, active dry yeast, MSG, excessive supplementation and return of some dairy fats and grains previously and in our opinion sometimes unnecessarily removed.

After eight weeks, the participating families received a questionnaire on their child's progress with the diet. Not all families returned the questionnaire. Of the original 69 individuals, we met 52 again to review their progress and update their diets as needed. 5 that we didn't meet again are still part of the group because we still have contact via email. We also met an additional 58 new participants. Their progress will also be charted and reviewed in future reports. This paper includes statistical data on the total group, including family medical history, co-occurring conditions and other data we consider pertinent.

Background - The way to recovery

To aim for recovery in autism, we first have to identify the cause. We believe that the most common cause of autism is an immune system choice during fetal development which leads to the targeting of a dietary pigment, lutein, by the immune system. We have described how and why this happens, and the evidence for it, in our literature. This immune choice also leads to a cascade of reactions which differ according to various factors, (immuno-)genetic, environmental, family history, diet, and the inherent strength of the individual. Treating the individual means assessing all of these factors, designing an individual diet with supplementation if needed, and recommending additional interventions and supports based on how the individual is responding.

We believe that one of the most significant findings in autism is an immature development of the limbic system – the emotional-language-learning system of the human and mammalian brain – which results in delay or arrest in language and emotional development. We believe that the continual immune response to dietary lutein is registered by the amygdala – the central clearing house of the limbic system – as a panic (fight-or-flight) reaction. Learning cannot proceed as long as the emotional center is in a state of panic – the mammalian experience of immediate threat to survival. After approximately 12 days lutein-free, the immune system begins to calm down and we often see the first signs of improvement. It usually takes up to 16 weeks to see the first signs of an awakening of the

limbic system, emotional expression and the availability for learning. This time frame is fairly consistent.

Once awakening begins, we assess where the individual is developmentally, and look at many therapeutic, educational, behavioral and sensory strategies which can bring about progress in these areas. This was the focus of many of the discussions we had with parents and professionals, as we plan the next stage in the recovery program.

Purpose

Many times there have been reported information for the autism population which includes high instance of numbers among immigrant populations for persons diagnosed on the autism spectrum, high numbers of close family members who have autoimmune disease, high incidence of co-occurrence in families and also studies which try to identify if the placement in the sibling roster can give clues to help unravel the mysteries of this syndrome. Currently there are many controversies also surrounding autism and these include blame cast upon the pharmaceutical-military-government- political-industrial powers. In peer review literature there is lacking substantial information which has been overlooked as a genetic cause has been investigated. Medical information has been very limited and signs, symptoms and commonly co-occurring conditions may be under-reported. These include, but are not exclusive to, vitiligo, easy bruising, prominent birth marks, inborn errors of metabolism, visual impairment, hearing impairment and characteristics which include that some of these children are masters at escaping from protective environments. Parents who are coping with the autism diagnosis for their child are often, at some point, in a state of crisis, many are under pressure which most people who have no first hand knowledge of autism fail to understand. Among the modern tragedies which are rising in addition to autism are Sudden Infant Death Syndrome and Shaken Baby Syndrome resulting in death. Signs and symptoms of either or both conditions can occur also as vaccine reactions and can include brain swelling, bleeding iris and swelling. Few medical professionals are prepared to understand vaccine related injury and death and even fewer are prepared to report it and face the scrutiny of their peers. Families who have lost a child often face investigations. When those families are faced with the threat of jury trial is it so difficult to understand also that a grieving parent who has just lost a child would not be in the most coherent frame of mind and would, in some instances, be ready to accept blame in return for their partner (spouse) not having to also face a trial by jury. Whether the infant or child dies as a result of some unknown cause, medical negligence or a real trauma which occurred when a determined child escapes from protective confines and ends up drowned or perishes in a hostile environment from cold, hunger or accident is indeed a tragedy. It is also a tragedy when families are further torn to pieces by the collective which has done little or nothing to prevent the crisis.

Stages

Stages of development, stages of childhood, stages of disease, stages of change, stages of recovery – terms and descriptions which can be used to describe the most common scenarios and how these may be different in a particular person. Altered by many things, experience, environment, attitude, treatment and subject also to interpretation. Here we include some of the information obtained for a large group. Findings have been published previously also which suggest a large number of families who are among the immigrant population may have a higher incidence of autism. Why? The answer is no one really knows for sure. Is this a fact or just the finding in some studies? The reasons why people migrate are numerous and the types of people who migrate are variable. Circumstances, such as war, poverty, job opportunities, natural disasters and politics are key elements to some large migrations. There are other factors also which make the topic difficult to talk about openly such as prejudice and families of diverse ancestry may experience prejudice in their native community pr irreconcilable differences within their families. People of diverse ancestry may also use more than one language in their homes and both languages may not be the native language of the area in which they live or where their child or children attend school. As autism is recognized as a communication disorder how the information for this population is assimilated can make a difference in the understanding of how and why some therapies, programs and treatment opportunities an make a great deal of difference in the outcome for the individuals suffering from the condition. Many families who have a child or children with autism are also coping with other diseases, disorders and conditions within the family, statistically the incidence of especially autoimmune disease has been reported as higher in the families who have offspring with autism. This also might be a factor in the presentation of the signs and symptoms which are currently used to define autism in any individual. Collectively the group of people with autism have a higher incidence of autoimmune diseases in their immediate family and these families who are coping with disease conditions on a daily basis also go through stages as disease presentation changes. Stress, death, disbelief, disagreement, lack of knowledge about autism and increasingly limited options for

services, care and education for the child also factor into the home environments for many among the autism population. Ultimately poverty, separation, divorce and depression are a reality for many families facing autism. How the circumstances of the individuals with autism affect the outcome of the disease presentation is not well understood. A major question which is being debated now is vaccination and how or if vaccination is a factor in the increasing prevalence of autism. In each of the circumstances described here vaccination may indeed be a factor. Vaccination has been described as a causal factor for the increase in autoimmune diseases in the human population, a requirement for immigration, a requirement to obtain services. And, those most susceptible to vaccine reactions include people with autoimmune diseases, people who are impoverished and who may have sub-optimal diets, people with certain vitamin deficiencies, people with allergies to substances such as egg and gelatin and people who have altered immune systems and also those who have eczema.

Data

There have been studies and reports of various patterns in families with autism, including history of auto-immune disease and diverse ancestry. The purpose here was to gather statistical data on families involved in the ongoing dietary intervention study for reference purposes. After excluding 28 participants, we provide family history and participant information on 98 consecutive participants. This group was selected based on consultations performed from June 2002 to May 2003. Among the parents providing information are ten medical doctors.

Introduction

The total combined group consisted of 127 individuals, which includes 5 sibling pairs, leaving 122 families.

For the first group of 69 individuals (67 families) , 21 individuals (20 families) were excluded for various reasons:

Females excluded (reason)

Female numbers 103 – unknown data, collection impossible re: moved to new country.

Female number 122 – unknown data, collection impossible re: no follow-up communication

Males excluded (reason)

Male numbers 14, 86 provide full communication on dietary intervention but prefer not to provide family medical history or family medical history is unknown.

Male number 104 – unknown data, collection impossible re: moved to new country.

Male number 105 – one parent deceased. Family unable to maintain dietary intervention, did not provide family history.

Male numbers 108, 110, 111, 121 are confirmed as following dietary intervention but with limited data collection to date.

112-120 including 119 (twin pair) – confirmation has included that some are following the diet recommendations, but we have not met them a second time and do not have full information.

This leaves 48 individuals from the first group (47 families)

In the later starting group there are 58 individuals including 3 sibling pairs. Each sibling pair includes that both siblings are diagnosed with autism and each pair is comprised of one male and one female. The Family History information is included 1 time for each sibling pair, so that 55 families comprise the later starting group.

Five were excluded:

male number 27, 47, 77 – family history information not provided during first consultation. Also excluded from statistics on family history information from late starting group:

Female number 42 – diagnosis Angelman's Syndrome with epilepsy

Male number 41 – diagnosis Cerebral Palsy with epilepsy

This leaves 53 individuals (50 families) from the second group.

Total final participants in data group = 101, including 4 sets of sibling pairs**, leaving 97 families.**

Ancestry

43 of 97 have mixed/diverse ancestry, including two families with sibling pairs. The remaining 54 have non-mixed ancestry for at least 3 generations.

Family medical history: (information counted one time for each sib pair. Information refers to condition present in parent, grandparent or sibling – each condition is counted only one time per participant although multiple family members might report the same medical condition).

2 participants have at least one ancestor for which medical history is UNKNOWN
55 participants have family history of **high blood pressure (HBP)**
46 participants with family history of **diabetes** (one mother only during pregnancy)
26 participants have family history of **cancer** (2 were specified as leukemia)
22 participants have family history of **heart disease**
19 participants have family history of **asthma**
19 participants have family history of **eczema**
16 participants have family history of **allergy** (most commonly penicillin and shell fish, 2 grandparents were reported as allergic to their own sweat in unrelated individuals)
12 participants had family history of **arthritis**

Other elements of reported family history includes:
Anxiety/depression - 6
Low blood pressure - 3
Gout - 5
High cholesterol - 5
Parkinson's - 3
Alzheimer's - 4
Kidney disease and kidney failure - 7
Kernicterus - 1
Anemia 2 (1 mother also diabetic during pregnancy)
Rh neg mother - 1
CFS/Fibromyalgia - 3
Autism/Asperger in first or second degree relative - 8
ADD - 1
Thyroid condition (other than cancer) - 2
Elevated uric acid - 3
Migraine - 2
Epilepsy - 3
Colitis/gastritis - 2
Ulcer - 1
Thalassemia carrier - 1
Hep B pos - 1
Elevated clotting factor - 1
Osteoporosis - 1
Polycystic ovary - 1
Sibling (gifted or genius) – 2
Dyslexia (sibling) - 2
Microcephaly –(sibling) - 1
Difficult to conceive - 6 (one is only survivor of IVF triplet)

Families with no reported medical history of Heart disease, Cancer, Diabetes, High blood pressure - 14
Of these, 8 families were of diverse ancestry and include two individuals with incomplete family medical history – one adopted child, one with one or more missing relative. One of the four from a non-diverse background was said to be hard to conceive and an only child. One had a first cousin with developmental delay, the third had a parent or grandparent who died of kidney failure. 2 of these 14 individuals had a grandparent with Alzheimer's disease (one individual of diverse ancestry and one of non-diverse ancestry).

Of the 53 families which reported **high blood pressure** and stroke related death, 14 families reported no family history of cancer, heart disease or diabetes. 6 families reported both HBP and cancer. 3 reported HBP and heart disease. 4 reported HBP and heart disease. 4 reported HBP, cancer and heart disease.

Of the 45 families which reported **diabetes** in the family history, 7 of the families reported no concomitant HBP, cancer or heart disease. 12 reported HBP and diabetes. 9 reported HBP, cancer and diabetes . 6 reported diabetes, heart disease and HBP. 4 reported diabetes and heart disease. 4 reported diabetes, heart disease, HBP and cancer and 1 family reported cancer, heart disease and also diabetes w/o HBP.

Of the 11 families reporting **arthritis** all 11 families had also at least one other reported condition (cancer, heart disease, HBP or diabetes). 1 family reported arthritis, heart disease and HBP. 1 family

reported arthritis, cancer and diabetes. 1 family reported arthritis, heart disease and diabetes. 1 family reported arthritis, heart disease, HBP and diabetes. 1 family reported arthritis, heart disease, cancer, HBP and diabetes which included a brother sister sibling pair, both with ASD. 3 families reported arthritis and HBP which included a brother-sister sibling pair both with ASD; male was difficult to conceive and both the male and female had also G6PD. 6 families reported arthritis and also diabetes, with diabetes being the only concomitant condition reported for 3 of these families. Thus 4 families in the arthritis group reported also heart disease. 2 reported also cancer. 6 reported also HBP. 5 reported also diabetes.
Heart disease. One family reported medical history of heart disease and no other medical conditions. One family reported heart disease, arthritis and Alzheimer's disease.

Co-occurring diagnosis in ASD participants
Deafness - 1
Asthma - 5
Astigmatism - 1
Retinopathy of Prematurity - 1
Epilepsy [Two of these had also Tuberous Sclerosis] - 9
Febrile seizures - 1
Tuberous Sclerosis - 2 (both TS individuals were males and both were one of a twin pair with unaffected twin. Twin siblings of TS males were one male – one female)
Oligodendroglioma tumor - 1
PRQQ (inborn error) - 1
G6PD (inborn error) - 3
[Note: 3 disqualified individuals were also recorded as G6PD and one sibling had also G6PD]
Vitiligo - 13
Café au lait birth marks - 18
Premature (w jaundice - 6) (w/o jaundice – 2) – 8
Other birth trauma - 21
(i.e. muconium aspiration, forceps, vacuum, asphyxia, emergency C-section)
Jaundice at birth who were NOT premature - 39
Diabetes - 0
Other:
Easy bruising - 8
Frequent nose bleeds - 1
Large head circumference - 8
Special circumstances:
Gallstones 1, Appendectomy 1, Gastroenteritis 1, Tonsillectomy 2

Sibling roster for ASD children
69 in the original group, 58 in the later group.
44 of 127 are an **ONLY child** (this includes those excluded from the Family history documentation. Of these 1 had an alternative diagnosis of Cerebral Palsy and 1 an alternative diagnosis of Angleman's syndrome).
31 are youngest siblings in multiple offspring families and of these 18 families had two offspring, 4 families had 3 offspring, 2 families had 4 offspring, 2 families had 5 offspring and 1 family had 7 offspring.
32 are the eldest sibling and of these 26 families have 2 offspring. Of the 26 families with two offspring there are 5 families with both offspring affected:
4 families have sibling pairs with both children affected and one each female/male. 1 family for which the ASD child is eldest have 5 children.
1 family had identical twin boys with both affected.
11 are the middle child of three offspring families. Of these middle children who are ASD, 3 are female children. 1 family is comprised of three female siblings and 1 family of three male siblings. All 9 remaining three children families where the eldest is ASD have both sex children.
1 male child is placed fourth out of five offspring in the family roster.
2 children are adopted and for the last one we have no information.

The child with also deafness was not identified until age 5.5, there may be others who have yet to be evaluated or diagnosed. Even though studies of autism reveal a heavy co-occurrence with visual impairment the number identified with visual impairment remains well below the statistical figure for

this type of impairment strongly indicating the knowledge of visual impairment in the medical community for patients with an ASD is inadequate in this area. Epilepsy was reported in 9 individuals: [Two of these had also TS] (In the excluded individuals; one with Angelman's syndrome and one with Cerebral Palsy also had epilepsy). Of the 9 presenting with epilepsy 2 had also Tuberous Sclerosis, 3 were reported to have suffered a birth trauma other than prematurity and none of the individuals who were premature had epilepsy. Of the three who had epilepsy and experienced a birth trauma all 3 families reported also HBP, one family reported both HBP and arthritis and the third Diabetes, HBP and heart disease. For the 4 who had epilepsy and no birth trauma all families reported also family history of diabetes. Even though family history included a significant number of parents and grandparents with diabetes there were NO reported diabetics among the ASD participants with or without other co-occurring conditions**.**