

GREAT ORMOND STREET HOSPITAL (GOSH) RARE DISEASES

The information in blue in the table below is what is shown in the GOSH website, presumably written by the professor or doctor. The writing in black italics are my comments and questions. Since my answers would be the same for many of the diseases, I have only made comment the first few diseases.

Every professor listed in the table below was asked whether they had ever considered that the disease that they are listed as investigating could be caused by drugs. They were informed that their names, titles and university would be published together with my questions that I sent them and their responses, if any.

In my letter to them, I included a copy of my articles stating that asthma and diabetes are caused iatrogenic, that is the result of medical treatment, by drugs. They can be seen in the 'Asthma and Diabetes' page. *No* professor answered my questions. As a result of their *silence*, I conclude that every single one of them they had already considered the possibility that the disease that they are researching could have been caused by drugs, or considered that the disease might be iatrogenic after reading articles on my website.

They might also have read Professor Ian Hall's answers to my asthma questions which I counter argued in red and capitals, because I felt that his answers were evasive and posted them online. As a result, they might have been concerned that I would do likewise with their answers.

From that, I conclude that they believe that the rare diseases that they are being paid to research, are quite likely the result of drug exposure.

After publication of this list, every professor was contacted and invited to comment. If any of them choose to provide comments, they will be published individually in the section following this page.



In my opinion, it's about time that justice prevailed and if drugs are to blame for rare diseases or congenital defects, compensation should be awarded to the unfortunate victims. Some law firms in many countries work on a no win no fee basis.



There are many congenital heart defects, hypospadias and penile as well as limb abnormalities as a result of women taking drugs during pregnancy. Unfortunately, the British National Formulary (BNF) which doctors in the UK use to prescribe drugs for patients, states for many antibiotics such as penicillins and cephalosporins, that for PREGNANCY there are 'No known to be harmful'. This is an appalling statement to make since studies have never been done.

I have been in contact with the Editor of the BNF many times during the summer of 2023 over the dose of amoxicillin, that has been doubled and for some children quadrupled over the years, and intend to contact them over this grossly misleading statement which informs doctors and patients that certain drugs are safe to take during pregnancy, when I believe that drugs taken during pregnancy are blighting the lives of many.


In the UK statistics are collected but no one seems to be interested in discovering the cause. There will be a Questionnaire on this website soon in the 'Justice for Victims' section in the hope that victims or the parents of victims complete the quick questionnaire. There are law firms who work on a no win no fee basis. The more victims who submit a completed questionnaire, the greater the chance of preventing these conditions and of gaining compensation if pharmaceutical compounds are to blame. If any drugs are suspected of causing birth defects or diseases, copies of medical records will be required.

	PROFESSOR OR DOCTOR	DISEASES BEING INVESTIGATED
1	Professor Francesco Muntoni Chair of Paediatric Neurology UCL GOS Institute of Child Health f.muntoni@ucl.ac.uk	Alpha-Sarcoglycanopathy Becker muscular dystrophy Beta-Sarcoglycanopathy Calpain-deficient limb girdle muscular dystrophy (LGMD) Centronuclear myopathies Congenital Muscular Dystrophies (CMD); CMD type 1B, CMD type 1c, CMD1D, dysferlin deficient, gamma-sarcoglycan deficiency Congenital distal spinal muscular atrophy (SMA) Duchenne Muscular Dystrophy Emery-Dreifuss muscular dystrophy Facioscapulohumeral dystrophy

		<p>Muscle eye brain disease (MEB)</p> <p>Myofibrillar myopathy</p> <p>Myotonic dystrophy</p> <p>Nemaline myopathy</p> <p>Peripheral neuropathy</p> <p>Giant axonal neuropathy</p> <p>Rare demyelinating neuropathies</p> <p>Rigid spine syndrome</p> <p>Spinal muscular atrophy</p> <p><i>I suspect that any slight variation in symptoms of a child with a neuropathy of myopathy is listed as having a rare disease. The more diseases a professor can list the more likely he may be to get funding.</i></p>
2	<p>Professor Detlef Bockenhauer</p> <p>d.bockenhauer.ucl.ac.uk</p>	<p>Autosomal dominant hypocalcemia is characterized by low levels of calcium in the blood.</p>
3	<p>Professor Phil Beales</p> <p>Professor of Medical and Molecular Genetics</p>  <p>p.beales@ucl.ac.uk</p>	<p>Bardet-Biedl Syndrome is a disorder that affects many parts of the body. The signs and symptoms of this condition vary among affected individuals.</p> <p><i>Professor Beales is said to have discovered over 40 disease related genes in the last decade. Drugs and chemical exposure during pregnancy are known to cause chromosomal alterations. So the most ethical thing to do would be to ask whether the mother or child has been exposed to drugs or chemicals such as alcohol.</i></p> <p><i>In Australia where entire houses may be sprayed with pesticides, one should also ask whether there was any exposure to pesticides.</i></p>

4	<p>Professor Anna Martinez</p> <p>anna.martinez@gosh.nhs.uk</p>	<p>Dystrophic and junctional epidermolysis bullosa is a group of genetic conditions that cause the skin to be very fragile and blister easily. Blisters and skin erosions form in response to minor injury or friction, such as rubbing or scratching.</p>
5	<p>Professor Juan Kaski</p> <p>Professor of Paediatric Inherited Cardiovascular Medicine</p>  <p>j.kaski@ucl.ac.uk</p>	<p>Paediatric hypertrophic cardiomyopathy is a rare heart condition that affects infants and children. Several different types of cardiomyopathy exist, and the specific symptoms vary from time to time.</p> <p><i>Government statistics show that Congenital Heart Defects are the most frequently occurring birth defect in the UK and in some other countries.</i></p> <p><i>The possible involvement of drugs in causing a birth defect(s) can easily be investigated and in my opinion should be the first course of action if a child has a birth defect at birth or presents with one at a later date. This is because it may be a birth defect that is not easily detected at birth.</i></p>
6	<p>Professor Stephen Hart</p>  <p>s.hart@ucl.ac.uk</p>	<p>CYSTIC FIBROSIS - is a genetic disorder that affects mostly the lungs, but also the pancreas, liver, kidneys, and intestine. Long-term issues include difficulty breathing and coughing up mucus as a result of frequent lung infections.</p> <p><i>Cystic Fibrosis was first reported in 1938 by Dr Dorothy Andersen.</i></p> <p><i>Drugs started being mass produced in the late nineteenth century in the UK and presumably from that time onwards, doctors began to prescribe more drugs as they became more affordable. Cystic Fibrosis therefore is in my opinion likely to be an iatrogenic disease and professors should ask the parents of children with cystic fibrosis if the mother took any drugs during pregnancy.</i></p> <p><i>This could enable the disease to be eradicated.</i></p>

7	<p>Professor Shamima Rahman</p> <p>Professor of Paediatric Metabolic Medicine</p> <p>shamima.rahman@ucl.ac.uk</p>	<p>Complex multi-system mitochondrial disorders of infancy and childhood</p> <p>Mitochondrial cardiomyopathies</p>
8	<p>Professor Lucy Wedderburn</p> <p>l.wedderburn@ucl.ac.uk</p>	<p>Juvenile Dermatomyositis (JDM) affects the skin and muscles and frequently other parts of the body including joints, lungs, gut and blood vessels.</p>
10	<p>Professor Philippa Mills</p> <p>p.mills@ucl.ac.uk</p>	<p>All inherited metabolic diseases</p> <p><i>What tests and clinical studies have been done to prove that the disease is inherited? Were parents questioned about chemical exposure including alcohol, smoking and drugs?</i></p>
10	<p>Professor David Skuse</p> <p>d.skuse@ucl.ac.uk</p>	<p>Autistic spectrum disorder (ASD) is a condition that affects social interaction, communication, interests and behaviour</p>
11	<p>Professor Frederique Liegeois</p> <p>f.liegeois@ucl.ac.uk</p>	<p>Autoimmune encephalitis refers to a group of conditions that occur when the body's immune mistakenly attacks healthy brain cells, leading to inflammation of the brain. People with autoimmune encephalitis may have various neurologic and/or psychiatric symptoms.</p>
12	<p>Professor Mehui Dattani</p> <p>Head of Paediatric Endocrinology</p> <p>m.dattani@ucl.ac.uk</p>	<p>CHARGE syndrome is a recognizable genetic syndrome with known pattern of features. Babies with CHARGE syndrome are often born with life-threatening birth defects.</p> <p><i>The parents of any baby born with birth defects should be questioned about chemical exposure especially drugs taken during pregnancy.</i></p>
13	<p>Professor Davod Goldblatt</p> <p>Professor of Vaccinology and Immunology</p>	<p>Chronic granulomatous disease. Development of clusters of blisters in specific areas of the body.</p> <p><i>I wonder if Davod has ever questioned whether the child had taken any drugs prior to the onset of</i></p>

	 <p>d.goldblatt@ucl.ac.uk</p>	<p><i>symptoms and whether there had ever been a period devoid of symptoms?</i></p>
14	<p>Professor Paul Winyard</p> <p>p.winyard@ucl.ac.uk</p>	<p>Autosomal dominant polycystic kidney disease (ADPKD) is a genetic disorder characterized by the growth of numerous cysts in the kidneys. It is the most common inherited disorder of the kidneys. Symptoms usually develop between the ages of 30 and 40, but they can begin earlier, even in childhood. The most common symptoms are pain in the back and sides and headaches.</p>
15	<p>Dr Rachel Knowles</p> <p>rachel.knowles@ucl.ac.uk</p>	<p>Congenital hypothyroidism</p> <p><i>Chemical exposure of the foetus during pregnancy can cause damage to the chromosomes and organs, so it is possible that the thyroid gland may be adversely affected by drugs.</i></p>
16	<p>Dr Vileya Ganesan</p> <p>v.ganesan@ucl.ac.uk</p>	<p>Moyamoya</p>
17	<p>Dr Shahin Moledina</p> <p>shanin.moledina@gosh.nhs.uk</p>	<p>Paediatric Myelodysplastic Syndromes</p>
18	<p>Professor Christopher Clark</p>	<p>Rasmussen's encephalitis</p>

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19	<p>Professor Jugnoo Rahi</p> <p>j.rahi@ucl.ac.uk</p>	<p>Retinal dystrophies</p> <p><i>In the past many children in Japan who were exposed to a drug during the mother's pregnancy were born blind, so there could be other drugs that can damage the eye.</i></p> <p><i>I believe that myopia (short sightedness) is a result of chemical exposure, either drugs or alcohol, during pregnancy.</i></p>
20	<p>Professor Mehui Dattani</p> <p>m.dattani@ucl.ac.uk</p>	<p>Septo-optic dysplasia (SOD)</p> <p><i>In the past many children in Japan who were exposed to a drug during the mother's pregnancy were born blind, so there could be other drugs that can damage the eye.</i></p> <p><i>I believe that myopia (short sightedness) is a result of chemical exposure, either drugs or alcohol, during pregnancy.</i></p>
21	<p>Professor Gudrun Moore</p> <p>gudrun.moore@ucl.ac.uk</p>	<p>Silver Russell-Syndrome is a rare disorder characterized by intrauterine growth retardation and postnatal growth deficiency along with a handful of common physical characteristics and a range of other symptoms</p>
22	<p>Professor Neil Sebire</p> <p>neil.sebire@gosh.nhs.uk</p>	<p>Sudden Infant Death Syndrome (SIDS). Experts believe SIDS...affects babies vulnerable to certain environmental stresses.</p> <p><i>Some babies are given drugs after birth.</i></p>
23	<p>Professor Lyn Chitty</p> <p>l.chitty@ucl.ac.uk</p>	<p>Usher Syndrome is a condition characterized by partial or total hearing loss that worsens over time.</p> <p><i>There are over 200 Ototoxic drugs that can damage hearing.</i></p>
24	<p>Dr Neil Shah</p> <p>neil.shah@gosh.nhs.uk</p>	<p>Very-early-onset IBD (VEO-IBD) is diagnosed in children younger than age six.</p> <p>Antibiotics such as penicillins can damage the gut and cause celiac disease, so it is highly likely that they can cause irritable bowel disease (IBD).</p>

25	<p>Dr Claire Booth</p> <p>drclairebooth@gmail.com</p>	<p>Walker Warburg syndrome is an inherited disorder that affects development of the muscles, brain and eyes. It is the most severe of a group of genetic conditions known as congenital muscular dystrophies, which cause muscle weakness and wasting (atrophy) beginning very early in life.</p> <p><i>Since the condition begins very early in life, it wouldn't take much to discover what drugs if any were taken during pregnancy and by the child before diagnosis.</i></p> <p><i>And on what basis has it been categorized as an inherited disorder? Does either grandparent also suffer from the condition? If so, the grandmother might also have taken a drug during pregnancy.</i></p>
26	<p>Professor Kathy Pritchard-Jones</p> <p>k.pritchard-jones@ucl.ac.uk</p>	<p>Wilms tumour a type of kidney (renal) cancer in children.</p> <p><i>I have come across one child who was born with a cancer that the parents were not told about, despite there being an operation to remove it. Sometimes doctors decide that it is best for a patient not to be told the whole truth. As a result of this information obtained during my research, I believe that chemical exposure by the foetus during pregnancy can cause cancer.</i></p>