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Moms Who Love Their Babies to Death and

the Dads Who Stand Behind Them.

Munchausen by Proxy Syndrome

Gentlemen, in the past when I have appeared before you I have made a determined effort to refrain from serious, thought provoking subjects that might unnecessarily attract serious scrutiny from my betters. Instead, I have always attempted a more jocular approach to my paper presentations in hopes that a bit of frivolity would assuage your critical wrath.

Tonight, however, I shall travel a road that most Athenaeum members have ventured down at one time or another and shall speak to you on a subject that has for me more than a passing vocational interest. As some of you are aware a good part of my job related professional responsibilities are focused on what is commonly known as Child Protective Services, that is, the detection, prevention and treatment of child abuse, child sexual abuse and child neglect.

I would like to share with you a few thoughts concerning a perplexing and little known or understood child abuse phenomena which has been given the name of Munchausen By Proxy Syndrome. This name was derived from and named after Baron Von Munchausen, a German mercenary and raconteur born in 1720. After returning home from serving with the Russians against the Turks, the Baron spent the rest of his life impressing his friends with fanciful and highly unlikely stories of this wayfaring escapades. One of his associates published a collection of these preposterous tales, which added to the Baron's fame. The Baron's name and fame were rekindled in 1951 when an English physician, Dr. Richard Asher, described a psychiatric disorder whereby adults gave dramatic and untruthful physical histories along with the presentation of seemingly acute illnesses that were ultimately found to be false. Because of the completely

factitious nature of these medical histories, the disorder, Munchausen Syndrome was named after the Baron.

Munchausen Syndrome by-proxy is a different yet similar disorder. The by-proxy syndrome was first articulated in 1977 by another English physician, Dr. Roy Meadows, who described a case of a six year old girl who had recurrent bloody urine. The girl was subjected to repeated tests and hospitalizations before the urine in the blood findings were judged to be spurious and produced by the girl's own mother.

Munchausen by-Proxy Syndrome has been described as a variation of child abuse whereby the parent systematically fabricates illnesses in their children or intentionally induces symptoms by making their children gravely ill, or both. These parental behaviors may result in unnecessary examinations, treatments, hospitalizations and even death for the children involved. With the proxy syndrome the primary motivation of the parent involves his or her need to maintain a relationship with the medical system. By-proxy mothers, unlike well meaning but over-anxious parents, often tell out right falsehoods about their families backgrounds, medical histories and life experiences. The list of illnesses that have been presented in the by-proxy syndrome cover a remarkable range of organ systems and physical complaints. Some of the different factitious or induced symptoms for which children have been brought to the attention of physicians include abdominal pain, bleeding, diabetes, diarrhea, fevers, infections, lethargy, rashes, renal failure, seizures, cancer, vomiting, weight loss, cardiac arrest and the list goes on and on.

The name Munchausen Syndrome by-Proxy was coined from the Adult Munchausen Syndrome because it seemed to mimic the adult

disorder of illness fabrication but involved the use of a child as a type of proxy or substitute for the adults own body. Unfortunately, the similarity in name of the two disorders has engendered considerable confusion about the relationship between the adult factitious disorder and the by-proxy syndrome. The term "Munchausen Syndrome By Proxy", still widely in use, makes the unwarranted assumption that the proxy syndrome is simply a variant of the adult disorder. While it is true that some people share symptoms of both disorders, about 10 to 20% of known cases, researchers are now discovering that there seems to be distinct differences in population and behavior between the two syndromes.

Research wise the adult Munchausen Syndrome differs from by proxy in that it has been known and studied for a much longer period of time. The adult Munchausen syndrome is apparently more common in males than females. In contrast, the known by-proxy cases almost always involve the female parent. It does appear, however, that there is a significant minority of mothers (10 to 20%) engaged in the by-proxy behavior who also manifest the Adult Munchausen Syndrome.

Also, the Adult Munchausen patients' relationship with the medical community is usually quite different than the by-proxy mother's relationship with her child's physician.

The mother's relationship covers a more extended period and her attitude is characterized with admiration and appreciation toward the physician. In contrast, the adult Munchausen patient's relationship is generally brief and stormy with angry confrontations instigated by the patient.

While the majority of the known female by-proxy perpetrators are mothers using their natural children, there have been cases

involving adoptive mothers, foster mothers, day care operators, nurses, and grandmothers. Cases in which mother and father are jointly and knowingly involved in by proxy are rare. Much more common are cases in which the father is a passive colludor, turning a blind eye on what is happening and failing to help his child or support his partner with parenting.

By almost all accounts the mothers affected by the by-proxy syndrome appear totally devoted to their child. They are intensely interested in their child's medical problems and persistently pursue tests and procedures. The parent usually insists on remaining actively involved in caring for the child and is very reluctant to leave the hospital for any reason. They often develop first name relationships with nurses, physicians and ward staff. Yet a closer examination often reveals that these parents are not devoting themselves solely to their child during the hospital stay. They can often be found far from the children offering solace and emotional support to other mothers.

The by-proxy mother appears to have an intense need to be in a relationship with doctors and hospitals and to belong to a social circle whose common bond is caring for sick children. By-proxy parents are extremely knowledgeable about medical issues and questions. They offer highly elaborate, technically proficient medical histories that reveal a medical sophistication beyond their general fund of knowledge. Also, quite a number of these parents are connected professionally to the field of medicine, working as nurses, orderlies, medical transcriptionists and nurses aides.

Initially, at least, these mothers are very supportive of doctors and staff, despite the fact that their child's health may be deteriorating under these professionals' care. Often aggressive

about demanding new procedures and interventions for their child, they can get very angry when they do not get their way. When a by-proxy mother's claims are disbelieved by her physician, this disbelief can lead to disastrous consequences for her infant, even to death. She may be driven to act rashly in a desperate attempt to convince the doctors. This compulsion of these mothers to repeat their harming behavior and thus prove their child ill poses the greatest risks to the child but also offers the greatest hope for discovery. In situations where the child is being closely observed by medical staff and the usual fabrications created by the mother are being prevented, some by-proxy mothers may be compelled to up the ante in a desperate effort to prove their child is seriously ill and to keep the medical system engaged with this child.

Almost everyone who initially comes into contact with by-proxy syndrome experiences some resistance to believing that mothers could intentionally harm their children in this horrifying way. This common disbelief shared by doctors, hospital staff, social workers and court officials is in part engendered by the very dramatic discrepancies between the mother's public presentation of her relationships with her child and the private realities of these children. Adding to the disbelief are the extraordinary lengths to which some parents will go in order to establish a medical problem in their child.

One case describes a mother who gathered names of patients from the cystic fibrosis foundation under false pretenses and then called patients by phone in order to collect sputum for research. She then tried to use one of these samples to convince doctors that her child was ill with this serious disease.

Fathers whose wives are involved in the by-proxy syndrome are

generally observed to take a very passive role in their families, either through physical absence or by emotional distance from wife and child. Often these fathers appear removed from the medical problems of the child, and from the mother's intense involvement with the medical world. The mother dominates the parental decisions which involve their child's illness, and contrastingly, the fathers claim to be unaware of their child's problems. Many of the fathers are described as overly involved in their work. Some are absent from the home for long periods of time for such things as military duty, long distance truck driving and other kinds of specialized work. Rarely do these fathers find time to visit their child during one of many stays in the hospital.

Researchers have divided by-proxy parents into two basic types: "doctor addicts" and "active inducers". Active inducers are characterized by active and direct efforts on the part of the parent to induce dramatic symptoms of illness in the young child. "Active inducer" mothers have been described as cooperative, concerned, loving, calm, devoted and above suspicion. Their victims are usually infants or preschool children. Innumerable methods have been used by "active inducers" to induce medical symptoms in their children but just a few of these methods would include: injections of gasoline; suffocation; medication overdoses; vomiting inducement; poisoning; removing blood from the child and withholding treatment from a mildly sick child to make the illness appear worse.

The following is a case situation which dramatically illustrates the "active inducers" threatening behavior to her child. After 22 months of unsuccessful diagnostic procedures in a hospital setting in England to determine the cause of a baby's breathing problem, hospital staff concealed a video camera in the baby's room

and a police woman and nurse jointly monitored the scene. Sixteen hours after the onset of video monitoring, the child was observed asleep in his cubicle with only his mother in attendance. The mother moved a chair away from the bed and lowered the sides of the bed. She then placed a T-shirt on the bedding close to the child's face. Five minutes later she placed the garment over the baby's nose and mouth and forced his head down onto the mattress. He awoke immediately and struggled violently. After 10 seconds the police woman alerted the nurses who then went into the cubicle. Because of her own distress at what she had seen, the police officer apparently intervened prematurely by legal standards and so it was decided to continue surveillance of the mother and infant. Twenty minutes later when the child was asleep and the mother was again alone in the cubicle, she placed the baby in a supine position with his face upright and his arms tucked under the bedding. Ten minutes passed until she again applied the garment to his nose and mouth and forced his head onto the mattress. Again the child struggled violently. Forty two seconds later the nursing staff were alerted by the police and went into the cubicle. When confronted, the mother claimed that her son had woken screaming and that she was only comforting him.

The second type of by-proxy parent is the "Doctor Addict". The "Doctor Addicts" are described as obsessed with the goal of obtaining medical treatment for nonexistent illnesses in their children. Doctor addicts fall more into the category of reporting false histories and symptoms than of actually causing illnesses. However, there have been cases when parents have engaged in both types of by-proxy syndrome, both "Active Inducer" and "Doctor Addict".

The following is a typical case example of the by-proxy doctor

addict.

Christopher was 8 years old when he first came to the oncology clinic at a hospital in the Midwest for a general check up. His mother, Margaret, reported that the child had had Leukemia when he was 2 and had been treated with chemotherapy for 18 months at a hospital in another city. Christopher had been in remission for several years and had been brought to the hospital for a routine exam. He was given a bone marrow aspiration (a painful procedure involving inserting a needle in the base of the spine) and was scheduled for follow-up in 3 or 4 months.

Ten months later Christopher and Margaret returned. On this visit Margaret expressed concern that her son might be suffering a relapse. She reported that Christopher was experiencing low grade nausea, fatigue, night sweats, fever, abdominal pain, easy bruising, and severe headaches in the past month. Concerned by these symptoms, the clinic's attending physician admitted Christopher to the hos-pital for a series of tests.

By physical examination Christopher appeared to be healthy and in no apparent distress. He nevertheless confirmed his mother's reports of his symptoms. A series of blood tests were ordered for him as well as chest and abdominal X-rays, and another bone marrow aspiration.

During this second visit the mother provided more details of the family history. She reported that Christopher's father was wheelchair-bound due to a shooting accident years earlier. In addition, she said she had a son with multiple sclerosis and had had a daughter who died at age 3 of a brain tumor. She reported that she herself was suffering from a degenerative nerve disease and was eventually going to lose her ability to walk.

Margaret went on to tell about Christopher's medical history. Two years after his remission from cancer at age 2, he had had a recurrence of fevers, fatigue and respiratory distress. Margaret took him for treatment to a doctor in Arizona. She reported that because this doctor wanted to use some experimental drugs to treat her son, she took Christopher out of his care. She also reported that more recently Christopher had had some surgery for tumors in his abdomen.

Because this story was rather puzzling, this physician called the Arizona doctor, who reported that he had indeed seen Christopher a few years earlier, but that everything else the mother had reported about him was untrue. He was unable to confirm Margaret's reports of previous treatment. Far from recommending experimental drugs, he had actually confronted Margaret about what he suspected was fake information and mother and son never returned to his office.

Now quite suspicious of the entire medical picture, our inquiring doctor began calling all the hospitals and physicians on the mother's list. Many of the hospitals named by the mother had no record of Christopher's treatment. Margaret's own physician confirmed that she had some medical problems (but no serious neurological disorder). One of Christopher's oncologists said he had never diagnosed leukemia and had suspected that Margaret was fabricating her son's illness because of her ongoing reports of a series of "terrible diagnoses out of the blue" about other members of her family. But like all the other physicians before him, he had been unsure of how to proceed and was reluctant even to confront Margaret with his concerns.

At this point, a psychiatric consultant was called by our

doctor and asked to consult on this unusual case. After reviewing the data, he decided to meet with Margaret and her son. Far from appearing strange or psychotic, Margaret seemed to be an intelligent, articulate, and caring parent. As the physicians outlined the investigative steps they had taken and the contradictions in her story, she grew righteously indignant and proceeded to offer an almost believable explanation of each item that was challenged. During four hours of continuous meetings, the mother never acknowledged her fabrications. And Christopher, although withdrawn and sometimes tearful, always confirmed his mother's story saying "my mom wouldn't lie, why would she lie?"

Children such as Christopher exemplify those older children who have been involved as by-proxy victims over a period of time and form a collusion relationship with their abusive parent in assisting in the fabrication of illnesses.

My final by-proxy case example illustrates how an abusive parent can become involved in both the doctor addict and the active inducer forms of by-proxy syndrome: A six year old child was transferred from another hospital following a three week history of chronic diarrhea. After one week of hospitalization, it was apparent to the medical staff that the child's diarrhea was not physiologic in nature, given the multitude of normal tests and the cycling nature of the diarrhea. The child was subjected to numerous needle sticks for blood and numerous IV's were started. She underwent a colonoscopy with a biopsy and a small bowel biopsy, both of which were invasive procedures. A decision was made by the interdisciplinary team to separate the child from the mother to determine the basis of the diarrhea. The mother later admitted to a physician that she had in fact been feeding the child even though the feeding

orders were "nothing by mouth". The mother also related that the child's stools were really her own mixed with water. The mother later recanted this admission. The child's diarrhea ceased after the mother was prohibited from visiting the child without supervision. The family history revealed that there is also a two year old child in this family diagnosed as having a seizure disorder who had been treated with anti-convulsants. His electroencephalogram was normal but he was treated anyway because of the clinical history given by his mother.

Unlike the other forms of child abuse, the by-proxy syndrome does not have the usual indicators such as intense rage or indifference on the part of the parent. The by-proxy parent looks to all the world like a wonderfully, caring, self sacrificing individual who has a very close relationship with their children. Because of this paradoxical behavior, only the most blatantly obvious cases are ever reported and investigated. There is, however, a cluster of signs which assist doctors and social workers in defining what constitutes the by-proxy syndrome. Some of these signs would include: persistent or recurrent illnesses of the child for which medical causes cannot be found; major discrepancies between the child's medical history as presented by the parent and the actual clinical findings; symptoms and signs that do not occur when the child is separated from the parent; unusual symptoms, signs or medical course that do not make clinical sense; persistent failure of a child to tolerate or respond to medical therapy; a parent who appears unusually calm and often less concerned than the physician and may even spend time comforting the hospital staff; repeated hospitalizations and vigorous medical evaluations of the child without a definitive medical diagnosis; and lastly, a parent who

welcomes medical tests of the child even when the procedures are excessively painful.

In closing it should be mentioned that to date very little is really known regarding the causes of Munchausen By-Proxy Syndrome. But even more perplexing, the prospect for effective treatment of these disturbed parents is not very good at this time, and although only the more serious cases are coming to our attention, the numbers continue to climb as society becomes more aware of this dangerous and troubling phenomena.