One Family's Nightmare

Parents of sick child falsely accused of Munchausen Syndrome by Proxy (MSBP)

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Prologue to Mary O'Connor's Article

by Charles W. Lapp, M.D.

As a pediatrician who specializes in persons with CFS, I have been alarmed at the increasing number of families that have been disrupted by well-intentioned but poorly informed state agencies. My first case was from Australia where the State did not recognize the diagnosis of CFIDS, and removed a child from the home, placed her in foster care, and forced her to exercise and attend school. Of course she did very poorly, having been pushed emotionally and physically far beyond her abilities. All of this was instigated by unfeeling physicians who perceived the girl as “lazy" and her parents as "too lenient." Ironically, the very parents who loved and sought to protect their child were perceived by others as neglectful, and they were persecuted under the aegis of “child protection" laws.

In the accompanying article, Mary O'Connor relates first hand a similar situation as it occurred to her family in the United States, this time because a physician made a hasty and unsupported diagnosis of "Munchausen Syndrome by Proxy" or MSBP. This diagnosis, like "childhood neglect", is frequently considered when children do poorly in school and have multiple medical problems, but in very few cases can the diagnosis be supported by fact. MSBP is unique in that the child's illness is caused and perpetuated by a parent, usually a mother, who derives some secondary gain - some attention, some benefit - from that child's illness, resulting in unnecessary examinations, treatments, or hospitalizations. Mortality may be as high as 9%. Sadly, many physicians and social workers mistake the loving care of a concerned parent for neurosis and neglect; and many mistake chronic illness for a perverse illness career.

Not only does Mary's story make us painfully aware of what can happen when professionals misunderstand, but it urges us strongly to educate the professionals as to the symptoms of CFIDS and the physical limits that it places on its victims.

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One Family's Nightmare

by Mary O'Connor

Our family is an ordinary middle-class family. There is really nothing unusual about us. We attend church, vote, watch television - a conventional family. We were unprepared for the nightmare that happened to us. We tell our story in the hope that other families will be spared from this experience.

Josie became ill with CFIDS on July 11,1992. She was 11 years old. We had been on vacation and were on the way home. She woke that day with symptoms typical of flu -headache, muscle aches, nausea, and sore throat. After two weeks she began to have other symptoms - difficulty sleeping, walking, and thinking; sensitivity to light and sound and other neurological symptoms. Worse, her headaches and nausea intensified.

Josie had been diagnosed with CFIDS for a year when her pediatrician sent her to a neurologist for severe headaches. He told us CFIDS was not a real illness and wrote in her chart unknown to us, "Munchausen Syndrome by Proxy."

That is when our family's nightmare began.

Munchausen Syndrome by Proxy (MSBP) is a rare psychological illness in which a parent fakes a child's illness. The parent does horrible things to the child in order to gain attention. Although it is an uncommon form of child abuse, it is suspected when a child who is chronically ill but has "normal" exams does not readily respond to medical treatment.

Having a child with CFIDS, we had experienced suspicion. Specialists told us nothing was "seriously" wrong with Josie. "Send her back to school. Treat her like normal. She'll be fine," they advised. One said, "Don't you just want to shake her? I mean, if she were my daughter, I think I would just have to shake her [from frustration]." Doctors questioned whether she felt excessive pressure because of school. Nurses treated her as if she had done something wrong.

However, we never expected they would accuse us of child abuse and try to have her taken away!

Josie's pediatrician consulted with Dr. David Bell and followed his advice. After this pediatrician became ill, our new doctor dismissed Bell as "too conservative." She referred us to a local internist, Dr. Cichon, saying he had a "special interest" in CFIDS.

Over the next two months Dr. Cichon gave Josie IV gamma globulin, IV acyclovir and Zofran, Interferon injections, and more than 20 different oral medications. As she got steadily worse, his attitude changed. He noted in her chart that her pain was "possibly put on." He said things to me like, "You focus too much on Josie's symptoms. Josie gets too much attention. You are making things worse. Why don't you go back to work, and get a babysitter to take care of Josie?"

I thought the suggestion that I hire a babysitter to nurse my sick child while I went back to work as a nurse made no sense. Because I was afraid to antagonize him, I avoided saying so. Inside, I was upset, worried, and confused.

Josie's pain worsened. Dr. Cichon tried injectable Demerol, then IV Demerol. When she became so nauseated that she couldn't take fluids, he admitted her to the hospital.

Over the next days the staff made negative Judgments about us. An example of this: because there was heavy traffic as workmen renovated the unit, I kept Josie's door closed to keep her room quiet. Later we found the staff had charted "Mom appears angry, keeps door shut."

Four days after admission five of the physicians involved, including Dr. Desai, a psychiatrist, and the medical director of our HMO, had a meeting. They decided that Josie was toxic from medications and should be put in ICU for "detoxification." There they would "try to get rid of the protective family," and then would send her to a psychiatric hospital "since there is no good objective data [to prove she is sick]." We were not told of these decisions. Instead, Dr. Desai told us Josie had an eating disorder and should be transferred to a psychiatric hospital. We declined this recommendation.

The next day Dr. Cichon told David and me that the staff had read a recent article in Redbook about Munchausen by Proxy, and they now believed that was Josie's diagnosis. We couldn't believe he was serious! We thought that Dr. Cichon concurred with Josie's CFIDS diagnosis, that he understood and supported us.

But he didn't. I was "over-involved," he maintained, and should no longer stay with Josie in the hospital. He wrote later in her chart, "Patient still being overly mothered and protected by mom. Can't get mom to accept her potential worsening of child's underlying condition."

We had always stayed with Josie when she was in the hospital, and for good reason. On previous admissions she had been carelessly mistreated. For example, she had been left alone and helpless in a wheelchair in a dark hallway late at night because staff was too busy to take her back to her room after a test. We felt we had to be present to protect her from these kinds of inappropriate actions. David and I took turns staying with her at night, and I was there during the day when he was at work.

Josie had been unable to eat for a month. Her weight loss became critical. When the doctors decided on tube feeding, her improved nutrition helped her nausea, she began to eat, and she grew stronger and more animated. Her headache remained severe but she had more energy to return home.

We began to hope she would soon be able to.

Meanwhile, however, physicians met again. Three of them told us that Dr. Cichon could "no longer support a diagnosis of chronic fatigue syndrome," and that Josie and I had a "symbiotic relationship" and must be separated. They planned to permit us only two hours of visitation daily, enroll Josie in school and have a teacher begin classes in the hospital, require her to go to physical therapy, and require her weight to be 80 pounds before she could be discharged from the hospital. Then they left the room without discussion.

We requested a different psychiatrist to examine Josie and review her records. He found no indicators of abuse or eating disorder. This, and weight gain, secured Josie's discharge in spite of the committee of physicians. At home her condition deteriorated. Our pediatrician referred us to other doctors and to Children's Hospital in Boston. No one had suggestions other than to stop all medications. Later, when we tried to renew a medicine for pain, the pharmacist told us that he had been "ordered" by the HMO not to fill any further prescriptions for us. He added that "the HMO says they are turning the whole matter over to MRS." This meant Health and Rehabilitative Services - the state agency that investigates suspected child abuse.

We appealed to our pediatrician, who said this HMO was like "the Gestapo." She suggested she re-admit Josie to the hospital as this would "take care of MRS." She said this was all she could offer. Anguished but with no other alternative, we agreed.

Josie was placed in ICU where the medical director, Dr. Orlowski, ordered aspirin for Josie's pain and told us we could visit her two hours a day only. If we did not agree, he would not treat her. He also said he believed there were simple remedies for Josie's problems. "You have to trust me," he said. We didn't trust him, but faced with the HRS investigation and no other medical care for Josie, we felt forced to accept his demands.

The next days were agonizing. Josie phoned us constantly, crying pitifully, complaining of pain and nausea, asking for us to bring her home, asking why we couldn't be there with her. We tried to reassure her with what Dr. Orlowski said, that he would help her, that he was trying to understand what was going on. Our words, which we did not believe ourselves, sounded hollow and offered little comfort.

At one point a doctor took the phone away from Josie and refused to allow her to call. When she cried she was told to be quiet. At one point a nurse made fun of her by saying, "Josie's having a cow," when she was sobbing with pain. She was given placebos for her headaches.

After several days, Dr. Orlowski told us that Josie's diagnosis was drug dependency. He said this was not our fault, as "The doctors gave her the medications." At one time, he said, she did have CFIDS, but she has been cured. "Everything they gave her in the fall would have killed it," he claimed. "She is now suffering only from the drugs."

His treatment was a "contract" with Josie to get her nausea "under control." If she ate, she would be allowed time with us. He also told us that home schooling was the "wrong thing" for Josie, and she should be sent back to school. At the end of our conversation, extremely upset, I asked him to discharge Josie. He refused which meant we would have to go against medical advice to take her home. Still facing investigation by the HRS, we believed we had no choice but to acquiesce.

The next day an HRS investigator told us that a complaint filed against us was "child abuse by substance misuse/abuse." While we struggled to obtain Josie's medical records to refute this charge, the investigator met with Dr. Orlowski and was told that Josie's medications were "inconsistent with a diagnosis of CFIDS" and that her correct diagnosis was Munchausen Syndrome by Proxy and anorexia/bulimia. Desai, the psychiatrist who had insisted Josie's diagnosis was eating disorder, offered the opinion that Josie was in "immediate danger" in our care. As a result HRS petitioned the court to have Josie placed in foster care.

An emergency hearing was held the next morning. The judge, unable to see clearly who was right, ruled that Josie be released to us provided we follow "any and all" recommendations of Dr. Orlowski. Dr. Orlowski then ordered Josie transferred to a psychiatric hospital. When we refused, we were returned to court for not following his orders. This time Dr. Orlowski hedged his testimony about Josie's diagnosis; and she was again discharged to us; but we were still required to follow his orders.

Dr. Orlowski required Josie to see him each week, be weighed at the hospital, keep a log of everything she ate, and have random drug screens. She could have no medications of any kind. She had to return to public school full time immediately. We were also to have psychological evaluations and individual and family counseling at our expense. An HRS case worker would make regular visits to ensure our compliance with these rules. Josie returned home under the grave stress of constant fear that she would be taken from us. For days she cried. For months she had terrible nightmares. She had nothing to relieve her pain. She was in bed except for the time she was in school and for the weekly hospital trip. Because of headaches, nausea, and fatigue she often had to leave class to go to the nurse's office.

After two months, Dr. Orlowski decided that Josie had "classic depression." He ordered her to use an exercise machine for 10 minutes each night as his treatment. After the first attempt Josie collapsed. The next day she was too sick to go to school. After Josie was in bed five days, Dr. Orlowski remanded her to a psychiatric facility - even though Josie's counselor said she had no psychiatric condition and advised him against it.

Meanwhile the psychologist who performed the ordered evaluation had found no pathology in any of us and said MSBP was not a correct diagnosis. He recommended that Josie's symptoms be relieved by the use of medications, that home bound schooling be provided, and that we have counseling to help us deal with the crises we had experienced. Dr. Bell wrote a letter to the judge refuting the diagnosis of MSBP, and the therapists arranged by Dr. Orlowski also told the judge there was no psychopathology in our family. An additional psychiatric evaluation also concluded that MSBP was an incorrect diagnosis and that there was no evidence of family pathology.

Faced with this testimony and no evidence of drug abuse, HRS reversed itself. The judge closed our case in May, nine months after we saw the neurologist who wrote "Munchausen's Syndrome By Proxy" in Josie's chart, three months after the first court hearing, and after we spent some $30,000 in legal and medical fees.

However, we remain listed in the Central Registry, a national computer bank which contains files of all people accused of child abuse. This listing empowers HRS to place Josie in foster care immediately if we are again accused of abusing her, justifying their actions on "past case history." Josie herself says of these events: "I was frightened all the time. Everything was equally horrible - the ICU, school, the psychiatric hospital. I don't remember how I coped. I felt betrayed by the doctors, and I was confused about what was happening to me. I didn't understand all the different diagnoses they gave me, why they were withholding medications from me, why they sent me back to school, why they didn't believe me."

Since these events Josie has been severely ill. It is our belief that the terror and agony she endured at the hands of Drs. Cichon and Orlowski worsened her condition. Our lawyers said we could not sue for malpractice because there is no "proof" that they harmed her. They also inferred that bringing suit would put us at risk for another custody fight. Because physicians and insurance companies have more political power and financial resources than we do, we were unable to press our case.

[**Editor's note:** Mary's case is not an isolated story. Similar stories are still happening in the United States and in other countries.]

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