

Lynne Millican, RN, BSN, Paralegal  
April 20, 2000

Endometriosis Association International Headquarters  
Mary Lou Ballweg

8585 North 76th Place

Milwaukee, WI. 53223

Dear Ms. Ballweg and Endometriosis Association:

As you may or may not be aware, I am currently involved in filing an application for leave to file an appeal to the Supreme Judicial Court of Massachusetts regarding "treatment" by my healthcare providers. This matter involves, among others, lack of informed consent and human experimentation involving the "hazardous" agent Lupron (designation of hazardous being made by the National Institutes of Health and Occupational Safety and Health Administration).

On a public AOL board, alt. support.endometriosis, the following statements were posted on April 18, 2000 by author "jksmac" (of the Endometriosis Association [EA]):

"Lynne ... the EA doesn't have any official stance on Lupron. We have never recommended any treatment as people respond to each in so many different ways. This is not to say that we are not aware of the complaints of serious complications that some people have reported. We are aware and of course we are very concerned. Feel free to call and share your concerns. ... to speak to this point about the EA accepting money from TAP, I for the life of me cannot understand why so much time and energy is spent getting on the EA's case about this. The EA does not recommend that anybody take Lupron. That is fact pure and simple. ... No one is pushing Lupron. It's time to move on to more constructive matters at hand like finding a cure for endo (that takes a lot of money) and helping women cope with this disease (support and education take money too). ... You might not agree with the EA taking a neutral stance on Lupron (at the moment) but there are many many women who have been helped by taking this drug. Is the risk too high? Personally, I think maybe so, but you would also have a huge fight on your hands if you tried to take Lupron away ... Janet (jksmac@)."

I am hoping that you'll take a moment, or perhaps a few moments, to evaluate, or re-evaluate, as the case may be - and to help me and many many others as well.

Having personal knowledge of the extent of adverse, lingering, reactions to lupron not only to myself but to so many others, I am seeking a statement from the Endometriosis Association to clarify the above statements, and to request a supportive testimonial from you regarding the awareness that the EA has regarding "complaints of serious complications that some people have reported."

"Neutral[ity] ... at the moment", I would presume, would yield a supportive statement regarding the extent of complaints and illness the EA has been made aware from women following exposure to lupron, identification of the lack of informed consent involved, as well as the names of physicians who are addressing the care these lupron victims need (medically and legally), and the names of attorneys who are providing legal advocacy and representation. Since no one appears to have any luck with the latter two, I don't expect you to perform miracles here - but can hope so none the less! But I certainly would expect that you would be able to provide testimonial to the following.

- lack of informed consent involved with lupron, specifically to its hazardous nature and the alleged mechanisms of action
- a summarization of the complaints the EA has received from members (or non-members!) regarding post-lupron illness, including the date of initial awareness of EA of post-lupron problems
- a summarization of the advice the EA offers to women complaining about their experience and health, and specifically addressing where these women can go for medical care for their lupron-related (rather than endo-related) problems
- whether you or the EA have knowledge of any other litigation involving lupron (either represented by counsel or pro se)
- whether you or the EA have knowledge of any studies being conducted \*on\* victims of lupron to evaluate the post-lupron effects (and if so, who is conducting these studies)
- whether any MD that the EA associates with (past or present) ever voice(d) any concern about the serious health problems women complain about during and following lupron (i.e. including, but not limited to, neurological difficulties, memory loss, immune system abnormalities, cardiac arrhythmias, death)
- if any MD that the EA associates with (past or present) \*has\* voiced any concern, whether that individual or group has \*ever\* testified on behalf of a lupron plaintiff
- and if any MD that the EA associates with (past or present) has voiced any concern about the serious health problems women complain about during and following lupron, would this MD be willing to testify in any current or future litigation? (As I write there are several ongoing, besides mine).

If the EA can provide any further information or direction regarding where victims of lupron can go to in an attempt to access medicolegal advocacy following the use of lupron, I would be very appreciative. All lupron victims would be very appreciative.

I'm going to forward my public post regarding this issue, to provide further illustration of this matter for you, and I would ask that you note I have a deadline of 4/29/00 (therefore I will also publicly post on alt. support. endo and request someone aware of your email addy can forward asap) in which I should receive any comments for my lawsuit. I hope that you are able to assist me to bring attention to the plight of lupron victims, and are able to forward a timely response to me (email would be fine if time becomes an issue for you [as it is for me!]) for inclusion to the court.

I do wish to make it clear that the answers to the above questions have significance and importance beyond any timeliness for my court deadline or court decision in my situation, and so, if you or anyone at the EA are unable and/or unwilling to help me now and by April 29, 2000, I confess that I no doubt will ask these same questions again after 'my' deadline.

Thank you for your neutrality, and for any supportive testimonial to the court that you might be able to provide, now or in the future.

Sincerely,

Lynne Millican