Hello,

This email is being sent to you because at some point over the last 10 years you have contacted 'Lupron Victims Hub'. (Because this website's mailbox has been intermittently malfunctioning, I'm temporarily using this AOL account.) I'd like you to be aware of the below information, and to consider the following:

Would you be interested in participating in an online Survey related to the adverse effects of Lupron / GnRHas?

This Survey is intended for all genders and all ages, and would pertain to anyone who has taken Lupron (also known as leuprolide, leuprorelin, Prostap, Enantone, Procrin, Lucrin, Eligard, Viadur, among others) or any of the other GnRH analogs (i.e. Synarel, Nafarelin, Goserelin, Zoloft, Trelstar, Triptorelin, Decapeptyl, Gonapeptyl, Histrelin, Vantas, Supprelin, Buserelin, Suprefact, Suprecor.) For a more complete list of names for Lupron and other GnRHas, see http://lupronvictimshub.com/home/Other_Names.pdf . And for names of Lupron in other countries, see http://intmarketing266.blogspot.com/2010/11/pfizer-example-to-product-name.html .

In my opinion, this Survey represents a potentially important step, and is a very worthwhile endeavor (and I will be participating). The Survey is quite detailed and lengthy, and would likely involve at least an hour of your time (you can take the Survey all at once or if you prefer, you can spread it out over several sessions or days). Let me quote the first paragraph of the Survey:

"Increasing evidence is accumulating from doctors, scientists, patient groups and online discussion forums, whereby the substances finasteride, dutasteride, isotretinoin, saw palmetto extract, GnRH analogs, and antidepressants are causing consumers to suffer from what is often long-term, irreversible and serious health damage. … "

Please allow me a few moments of your time to provide you with a little background information -

Approximately 8 years ago I was contacted by a brilliant man from Geneva, Switzerland – "Awor" – who was very interested in Lupron's adverse event profile, and told me he'd been reading my website for 2 years. In subsequent phone conversations and emails I would learn Awor's health became so adversely affected by taking the drug 'Propecia' (finasteride) that he became involved in (among other endeavors) the following: forming a 'Propecia Help' group; involving scientists and organizing data collection of Propecia victims (i.e. labs, biopsies); proposed a novel hypothesis on the pathway of damage caused by Propecia; became self-taught at subjects like neurosteroids to the point where he was invited to *speak* at international neurosteroidal conferences; recognized there appears to be a similarity in the adverse event profile and post-drug damage experienced by a number of drugs; and Awor has been instrumental and closely involved with the development of this Survey (while his 'Propecia Help' co-administrator, "Axolotl", deserves the credit as its main architect).

Throughout the years Awor has been faithful in his interest in including Lupron/GnRHa victims in the work he has been doing, and we have collaborated towards that end on a few projects. In 2013, I served as the token Lupron 'representative', and, along with a number of Propecia victims, underwent lab testing ("3a-diol-G"). My abnormal results, which were similar to the abnormal values in the Propecia

samples, lends credence to Awor's novel hypothesis on the pathway of damage and supports the contention that several drugs can result in this pathway damage.

Awor and his team have been trying to interest scientists and researchers to study this seemingly 'divergent yet similar' group of drug victims for a while, and it would appear this Survey brings that goal within reach. To quote Awor: "The whole survey is heavily based on scientifically validated and widely accepted assessment instruments and scales, to ensure that the data will be as acceptable as possible to the scientific community." It is possible that when this Survey is completed and the aggregated data analyzed, there will be sufficient (? ample!) evidence to entice scientific study of this group of drug victims (Lupron/GnRHas being just one of the groups). And the Survey could hopefully garner NIH funding (within the category of 'rare diseases') so that substantive study can finally take place. That is the hope and the plan.

Lupron has had a fair amount of media exposure, and there's been Lupron victims' websites, and there's been Lupron law suits, and there's been Lupron petitions and Lupron Facebook pages – now we need post-Lupron damage data and scientific study. This intensive and detailed Survey holds significant potential to make that happen. And so, I would strongly urge you to consider participation.

If interested, 'Propecia Help' has created a 'welcome page' for Lupron/GnRHa victims' participation - https://forum.propeciahelp.com/t/lupron-victims-please-participate-in-survey/32573, and there are several steps to get to the Survey:

First, you'll need to "sign up" to create an account (with either your or an anonymous name, and select "GnRH Analogs" as your substance). You will subsequently receive an email with a link, which you need to click on to verify your account. Once this occurs, you are registered as a user in the forum. In order to receive the Survey, you'll have to return again to the 'welcome page' (the latter link) and hit "reply" to Awor's welcome message. It is necessary to leave/post some type of reply comment because in doing so you will trigger a notice to the site's administrator to send the 'Survey Link' to you … your "reply" can simply be a "Hi", a "Hello", an "I've registered", or whatever you would like to say about your Lupron/GnRHa experience. (And if you choose to do the Survey in several sittings, save the 'Survey Link' and your password so you can return to the Survey at any time to finish.)

As a final comment, please be aware that the 'Propecia Help' website (aside from this multi-drug adverse effects Survey and 'our' welcome page) is a forum for men to share information and experiences about the numerous adverse health effects encountered from using Propecia (finasteride) – many of which Lupron/GnRHa victims experience also. But because of the not uncommon negative effects of finasteride upon male genitals (including disfigurement), the site can contain sensitive subjects and unflinching dialogue. I pass this along because without knowing this, if exploring the 'Propecia Help' website, one might be initially put off or offended by the content, but please bear in mind this forum is where these men can discuss their serious adverse effects.

I have had the privilege of critiquing the latter stages of this Survey from the Lupron/GnRHa perspective, as well as beta testing the Survey, and despite having gone through this extensive Survey numerous times, I look forward to finally taking it 'for real' now that it has gone live. In summary, the Survey starts with some personal, social, somatic and drug substance (GnRHa) data, and, likely because Propecia has caused such a significant amount of adverse sexual effects, the Survey Questions begin with 'Sexual Symptoms'. (In Lupron/GnRHa's case, it is today commonly understood to cause near-universal male impotence, but there is little data/discussion of female effects beyond Lupron's labels identifying up to

11% and 19% of women in the studies experienced decreased libido. But it should be kept in mind that the original Lupron prostate cancer studies reported 2% and 4% of men experienced impotence – and we now know those statistics to be quite unbelievable [and completely absurd, especially in light of Lupron's established use as chemical castration for sex offenders]. This Survey could help provide some definitive data on women, as it seems probable that more women have experienced libido changes than the studies report.) The Survey Questions then continue to cover the following domains: 'Physical and Neurological Symptoms', 'Physical Changes', 'Mental and Emotional Symptoms', 'Impact on Quality of Life', 'Patient Satisfaction', 'Reactions to Therapy Attempts and Activities', and there is a section at the end to choose and/or add symptoms and diseases not otherwise covered by the Survey. There also is the opportunity, if you'd like, to upload anonymized lab tests, scans, etc. (and only aggregate data and analysis will be published).

And the Propecia administrators have posted an excellent description of the Survey, with FAQs - https://forum.propeciahelp.com/t/post-drug-syndrome-survey-faq-and-launch-announcement/34482 .

Okay Lupron/GnRHa victims … let's get some data collected! The precision and detail of this study is, imo, impressive, and I believe you will agree. And I know we all agree that as a group we most definitely need some data collection and scientific study. I'm keeping my arthritic fingers figuratively crossed.

Thank you very much for taking the time to read this, and thank you in advance to anyone able to participate. And I hope this note finds you doing okay, and that the New Year brings some help, hope, and justice.

And please pass along 'our' welcome link (https://forum.propeciahelp.com/t/lupron-victims-please-participate-in-survey/32573) to any of your fellow Lupron/GnRHa sufferers via email, social media, etc.

Best wishes,

Lynne Millican, RN, BSN, paralegal (disabled post-lupron)
Founder, Lupron Victims Hub
www.LupronVictimsHub.com
lynnemill@aol.com
Boston, MA.
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