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Editor's note: This English translation was done by a third party. The original digital report can be accessed [here](#).

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Post-Finasteride Syndrome: In Italy, there's a patient association

With nearly 16,000 reports of adverse reactions to finasteride, 61 confirmed suicides worldwide stemming from intake of finasteride, and 16 countries (including Italy) that have added post-finasteride syndrome (PFS) warnings to the drug's package insert, we are hearing more and more about this particular pathology.

The researchers who deal with PFS are few, just as there are few studies about the condition. So patient associations can do a great deal to increase awareness of PFS and make people—doctors and others—aware of this problem. In Italy, the reference organization is the Finasteride Victims Association, based in Treviso, while the American Post-Finasteride Syndrome Foundation is very active internationally.

As explained on the website of the PFS Foundation, PFS, which in the US was officially included in the rare disease databases of the Genetic and Rare Diseases Information Center (GARD) and of the National Organization for Rare Disorders (NORD), is characterized by serious side effects that may persist for a long time after stopping treatment with finasteride, an inhibitor of the enzyme 5-alpha reductase type II used to treat hair loss (Propecia, finasteride 1 mg) or enlarged prostate (Proscar, finasteride 5 mg).

These adverse events include sexual, neurological, physical and psychological problems: for example libido loss, erectile dysfunction, depression, suicidal impulses, anxiety, panic attacks, Peyronie's disease, penile narrowing, chronic testicular pain, gynecomastia, muscle atrophy, cognitive impairment and insomnia. The drug in question is available in tablet form for oral use, and only by prescription. Since there is a price difference, the less expensive 5mg format, intended for the treatment of prostatic hypertrophy, is also sold, even to patients with androgenic alopecia. In this case, therefore, the patient finds himself having to manually divide each tablet into 5 parts, a procedure that does not guarantee a correct intake of the drug.

“About a year and a half after I realized I was suffering from PFS, I turned to a law firm in Treviso,” says the President of the Finasteride Victims Association (AVF). “I explained my situation to him and, since I was already in contact with other young with the same problems, their advice was to found a real association. In this way we could be stronger, both from the point of view of communication, but also to guarantee the legal assistance of the associates or to form a group to lend ourselves to interviews and research. Thus, in 2017, the AVF was born.” The association has about 40 members, ages 20 to 40, all affected by the side effects, even serious ones, related to the intake of finasteride. In these cases, we talk about real PFS when these side effects become chronic, persisting for months and years after stopping the drug treatment.

The problems around which this disease revolves are delicate: the physical symptoms (from those related to the sexual sphere to fatigue) and the psychological ones (depression, anxiety, psychosis, etc.) mean that patients, especially the younger ones, do not feel they can talk about it in simple terms, especially from a medical point of view, as they lack the knowledge of the pathology and, even worse, the real understanding of what it entails.

“We would like more attention from the clinical world,” the President of AVF continues. “We are visited by andrologists and endocrinologists, but after routine analyses—which do not show any

alterations—they send us to a psychologist. Many patients with PFS are not recognized as such. The important thing would be official recognition of this syndrome, which could also give a further boost to research. Although awareness and research are still lacking, something is starting to move, thanks to the numerous reports of persistent finasteride-related side effects that reach pharmacovigilance agencies around the world. For example, the illustrative leaflets of the drugs containing the active ingredient have changed a lot compared to 10 years ago: today, a series of symptoms classified as persistent has been added.”

“For those patients who have already taken finasteride, and developed PFS, it is important to realize that, unfortunately at present, there are no known effective therapies,” emphasizes Philip Roberts, Patient Manager at the PFS Foundation.

“However, in the last seven years we’ve come a long way in terms of medical research. No one knows how long it will take to develop valid therapies for the condition, but we hope this happens within the next two to five years. In the meantime, of course, we need funding to continue to sponsor research projects. So we invite everyone to donate to research. For those men who have never taken finasteride, but are considering the use of the drug,” concludes Philip Roberts, “our advice is not to take it for any reason: Its many potential dangers far outweigh the probable benefits.”