

Cicatricial Pemphigoid.

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Hello all,

I recently lost my long-time friend, Bob – the man who was my partner for 14 years – to cicatricial pemphigoid, which is apparently a form of cancer of the mucous membranes.

According to his family, he first showed signs of this disease sometime around Christmas 2003.

Evidently, my friend didn't want to see very many people including his own family, because of the way the disease affected his appearance.

Why I say this, is because it was around that time that I felt as though he was pushing me away from him.

We were no longer in contact at all after his 71st birthday on February 23rd, 2004.

It wasn't until October 14th, 2004 that I actually learned that he'd passed away on July 28th, 2004.

Aside from being absolutely devastated over my loss, I also deeply regret not having stayed in touch with him, and as such, I never got the chance to visit him or take care of him when he was sick, let alone to even say goodbye.

My questions are:

- (1) Is this form of cancer very rare?
- (2) Would this particular type of cancer be caused or aggravated by lifestyle factors or traumatic events?
- (3) Are certain groups more susceptible to this disease than others (e.g., age, ethnicity, gender)?
- (4) Can a patient live relatively comfortably or independently up to a point, considering the condition?

- (5) Is much pain involved, or is there any way to ease the suffering of a patient with this disease (e.g., drugs, surgery, therapy)?
- (6) Do patients of this disease tend to experience more pain than any other type of cancer, especially in view of the fact that it is a disease which is so difficult to treat and respond to treatment?
- (7) Can this disease induce secondary conditions, such as diabetes and high-blood pressure?
- (8) What is the usual duration of this disease?
- (9) Would a patient with this disease be informed at the outset that they are suffering from a terminal illness?
- (10) Does this disease always end with the loss of the patient, or there cases of known survivors?

Sorry if these questions seem morbid, but I feel that I need to know that my friend received the best care available.

Either way, I would greatly appreciate receiving whatever information you may be able to provide.

Also, a referral to community resources which specialise in counselling family members and friends of people who've suffered from this disease could be helpful.

Although I've reached out to resources which I posted earlier, they were unable to address the particular issues I have surrounding this disease.

Thank you in advance for your support.

Sincerely,

Glen A. RITCHIE

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