



Patient Report

How Many of us Are There?

A Report by
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I've often wondered just how many PJS folks there are in the world. Estimates of incidence range from 1 in 8,000 to 1 in 280,000 per live births. Of the 6 billion people in the world, this means there might be between 20,000 and 750,000 people with PJS alive right now. Holy smokes.

I want to know where all these folks are. While reading abstracts I started jotting down numbers. Korea- 30 patients; Japan (1961-1974)- 222 patients; Netherlands- 61 patients in 21 families; Ontario, Canada- 10 patients; China- 18 patients; London- 72 patients in 12 families; USA- 85 patients in 46 families. This is still under 500 patients total.

There are 500 reported in the large, published studies, but 20,000 to 750,000 based on incidence estimates. Since the most of the information about PJS (including our very high risk of cancer) are based on published studies, it would help all of us to have more people included in those studies.

Why aren't there more PJS folks? Are we under-diagnosed? We have people in this group with freckles, polyps and multiple surgeries for them and cancer who weren't diagnosed until years after their first surgery. It is hard to get diagnosed with PJS. We've read many startling stories from people about how they (or a parent or grandparent) were finally diagnosed. PJS is a 50-year-old syndrome, but many doctors still don't know much about it.

Are we underreported? Probably. Many PJS patients can probably get away with visiting doctors on an as-needed basis. Those doctors might never report us or consider reporting us to a hereditary colon cancer registry. Sometimes I read case histories of PJS folks written by doctors from very obscure places, are those patients reported? I had to find the PJS registries and study and ask to be included. No doctor has ever written up a case history on me, even though I have an unusual PJS story.

Are we undercounted? If a doctor did want to report a PJS case, who would they report it to? In the North America and Europe, we have registries, but I doubt that they actually collect 100% of patients. Only a few case histories leak out of South America, the Middle East (except Israel), Russia and Africa. Chinese doctors wrote of their 18 PJS patients. If there are 30 in Korea and over 200 in Japan, China probably has a counting problem. I imagine that each nation has a different way of counting its patients, even if those patients are correctly diagnosed and reported.

We in Europe, North America and Australia feel isolated from one another. Imagine living in a place where the condition is barely acknowledged by the medical profession. I'm probably dreaming again, but I wish we could connect with PJS folks in out-of-the-way places. If they don't have access to e-mail, perhaps their doctors do. I am keeping an open mind.

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