

Talk:Mollaret's meningitis

WikiProject Medicine (Rated Low-importance)

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Why so definite?

My latest source doi:10.1136/jnnp.2003.034272 seems to indicate that the herpetic etiology of Mollaret's is not definite. That was 2004. This article has no source to indicate that anything has changed... JFW | T@lk 11:37, 26 October 2008 (UTC)

Seems so sure about things other websites don't say

I've noticed a lot of things on here seem to contradict even confident information on other sites. Read this article and then compare: <http://www.patient.co.uk/showdoc/40001266/> <http://children.webmd.com/vaccines/tc/meningitis-topic-overview> —Preceding unsigned comment added by 69.244.170.147 (talk) 06:55, 20 May 2009 (UTC)

Mollaret's Meningitis Support Group

Mollaret's Meningitis Support Group Mollaret's Meningitis Support Group ^[1] Daily Support Designed to HELP Mollaret's Meningitis Sufferers' This syndrome is very RARE. WE are OUR best SOURCE of information. Chronic Headaches, photo & phonophobia, fibromyalgia, PAIN etc

I belong to a support group for a rare type of meningitis, Mollaret's Meningitis, and we have been looking for a way to bring together all of our combined knowledge, research, and support, into one place...there are only about 60 documented cases (but I believe there really are soo many more) of Mollaret's and we have so far rounded up about 27 in our little group. Most often we are the ones educating the physicians about our illness and we are the ones doing the research, and we are the ones holding each other up. It has been life changing and life saving for some of us...recently a woman from a small town in was about to commit herself...found our site, took the information to her doctor, and was diagnosed with Mollaret's.

Our site started from a simple post on Facebook, the larger Meningitis group, I made a small post about Recurrent Meningitis...and a few months later got a reply from Diane in Ithaca, and then wow...we started finding each other. Michelle Whitmore-Light brought us on to our own site on the ning network (and she has been paying for it herself all this time!) Michelle is our backbone and our cheerleader, she will phone you or your mother if she hasn't heard from you in a while...she is our driving spirit, I am the techy geek researcher type, behind her.

Recently I was visiting the Mayo Hospital in Arizona and Michelle and her husband Jim came and spent a night at the same hotel...wow. Face to face with someone who has lived through the same things I have. I can't describe to you how much it meant to meet someone who has gone through the same things I have, how many things we didn't realize were related...how much we shared, and how much everyone of us needs to have this opportunity. Having an 'invisible' illness can be so hard sometimes, it is such a relief to be around people that actually get it, they understand how you feel, you don't have to justify or explain....not validation, but just...acceptance.

It is time to form our own organization...I see that our first step would be forming a formal patient group, but we are so much more than that, and intend to be so much more than that for those that need us.

" We are the researchers, the guinea pigs, the cheerleaders, the support team, the crisis line...we need to step out on our own and let all of those who suffer from, or who suffer with someone with Mollaret's Meningitis, that there is a place to go and that they are not alone."

Most of us operate at about 20 - 60%, but as a group we are always 110%.

Any assistance, resources, contacts, references, any help your could provide would be so greatly appreciated.

Thank you again for your time and assistance.

Treena Blomquist treena_blomquist@yahoo.ca --Treena b (talk) 08:45, 16 September 2010 (UTC)

References

[1] <http://mollaretsmeningitus.ning.com/>

Article Sources and Contributors

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