

Reports on September 16 2007 from group leaders from Vernon, British Columbia Manitoba, Nova Scotia, Ontario, (Ottawa and Toronto), and Saskatchewan.

CNETS CANADA Membership Report from Vernon, Okanagan Valley, British Columbia

I have had an ongoing notice in our local paper in starting a support group in our area. I have had 3 calls, one call from a lady who's sister has Carcinoid, the other from a lady in her 60's that had a Carcinoid removed from her stomach (and told not to worry about it) and the other a lady in her 70's who is basically now palliative, (had a tumour removed from her stomach 2 years ago and told not to worry, it's only a Carcinoid) Anyway that is my report, I feel even with this little response I have made a difference already.

Joanne Ferguson.

CNETS CANADA Membership Report from Manitoba

Our little support group has grown quite significantly from W.T. and Garry and I just a couple of years ago to a total of 11 noids plus partners to date.

Only one of the eleven is not in regular contact with the group. The last time we communicated she told me her mother (the patient) was not ready for any type of group activity.

The rest of us meet and communicate by phone and email on a regular basis and are very grateful to have found each other. We have exchanged a lot of valuable information with everyone bending over backwards to help in any way they can. One of us is now being treated in London as a direct result of info he got from the rest of our group.

Dr. W is now actively telling his other noid patients about us. He is telling them to look for our contact info on the internet. I haven't had any results from info I have left at other medical centers yet.

We should probably be called the Manitoba Support Group since only 4 of our group live in Winnipeg. The rest are all from smaller communities outside Winnipeg. DA is from Brandon, a two hour drive away, but she came to our last meeting!

Silvia Steinhilber

CNETS CANADA Membership Report from Nova Scotia

As I am situated in Nova Scotia about 400 kilometers from our largest city Halifax, I am at a disadvantage to having meetings in the capital city.

However, if and when I receive the names of several of our co-carcinoids, I would gladly put together an agenda for a meeting or at least teleconference to talk to each other. To date, I have not received any contact from other carcinoids in Nova Scotia with the exception of P and her father's information. He is in Halifax and I do not know if he is able to attend meetings or not. I have been in contact with several carcinoids that I feel have become good friends and contacts but they are not in NS. I would love for my name and number to be continued to get out there for other Nova Scotians to contact. I'm sure in time this will happen.

As I have some limitations, I haven't to date put up notices in my local cancer center but that is a great idea and I will follow up with some of our information. I am thinking of a zebra poster that briefly explains Carcinoid and our national group contact number. I don't think I will put my personal phone number on a global site like that for the public but will gladly be routed through CNETS Canada as a contact. Let me know what you think?

Do we have a countrywide list of carcinoids to date? Do we know how many are diagnosed and living in each province? Can we find out?

Look forward to hearing from you.

Colette Morrison

CNETS CANADA Ontario.

Ottawa/Gatineau Area Support Group Report February 2007

The Ottawa/Gatineau Area Support Group for Carcinoid Patients had their initial meeting on February 24, 2007.

Six "Noids", out of 7 identified, attended this first get together along with 4 care givers. The group felt that the very good turnout showed the importance attached to meeting other people living or dealing with carcinoid. Each "Noid" introduced themselves and their caregiver and gave a short synopsis of when and how they were diagnosed and history of treatment to date. The sharing of information and experiences was frank and useful. All agreed to keep in touch via E-mail. While one person lives too far away to easily attend a future meeting, the others voiced a preference to meeting again in three months time.

Light refreshments were served after which the meeting adjourned.

Morley Dore

CNETS CANADA Saskatchewan Membership Report September 2007

In Saskatchewan we have only had one "formal" meeting due to weather, distances and health issues. Email & the phone is the mainstay for our support. Our first meeting we just introduced ourselves and each person gave a brief history about themselves. It was a good meeting as people could compare notes regarding doctors, tests, treatments etc., and names could now be put to faces. Due to the distance factor with people coming from all four corners of the province I am hoping to get one organized for after Thanksgiving before the snow flies.

Marlis Duff.