

Research 101 for brain tumour patients and carers

THE IBTA receives enquiries from patients and caregivers around the world. We can't offer medical advice or funds for medical expenses unfortunately.

One of the common types of enquiry comes from people who are desperate to discover if there is "something else out there" that could help their loved one. This might be their first attempt at research of any kind. We cannot undertake the research for them but we can give them some guidance as to how to go about researching in the recognised databases.

The following is an anonymised sequence of emails between the IBTA and a mother in North America. Some readers might find the advice useful. ■

The enquiry:

From: xxxxxxxx **To:** chair@theibta.org
Subject: Anaplastic Oligodendroglioma **Sent:** Monday, 2 January 2012 5:52 AM

xxxxxxx

Is there a world expert/centre for this malignant tumour type? I have tried to search by tumour type/brain tumour treatment centre/survival rates, but to no avail.

Wouldn't this information be valuable to patients and family? Which brain tumour centres have the longest rates of survival? Which brain tumour centres will disclose all experimental treatments that may be available to their patients at the beginning of treatment? So many patients are offered experimental treatments only after 'standard of care' has failed at which point they are physically and mentally worn down. Which brain tumour centres will give their patients a choice (standard or experimental) right at the get-go? Which brain tumour centres are considered the world's leading-edge centres?

We live in Xxxxxxx where our daughter's (age 25) treatment is given under provincial government's approved 'standard of care'. We are so fortunate to have access to a major medical facility known as (the) Xxxxxxxxxx at Xxxxxxxx Hospital, but, as you know all too well, the 'standard of care' doesn't do much for this disease. It's so frustrating. "Insanity is doing the same thing, over and over again, but expecting different results" (B.Franklin).

Would appreciate IBTA's insights as to which brain tumour centres and/or oncologists are considered the most progressive, leading-edge in the world.

PHILIPPINE BRAIN TUMOR ALLIANCE



We are committed to improving the lives of those affected by brain tumors. Educating & empowering them & their families to improve the quality of their lives.

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The response:

From: chair@theibta.org **To:** xxxxxxxxxx
Subject: Re: Anaplastic Oligodendroglioma **Sent:** Monday, 2 January 2012 10:52 AM

Dear Ms Xxxxxxx,

Thank you for your email. I am sorry to read about your daughter's diagnosis, brain tumours can be a devastating disease but oligodendrogliomas have a better prognosis than, say, glioblastomas, as I am sure you have discovered by now.

I can understand your desire to find out as much information as possible about oligodendrogliomas. My late wife was diagnosed with a glioblastoma and I knew nothing about it in the first month until I did some research.

As far as I am aware, there is no world centre or one single expert for anaplastic oligodendrogliomas (oligos). Much of the research involving oligos is within glioma research - in tandem with oligoastrocytoma research - where there is a focus on glioblastoma multiforme. However, I am sure there are researchers who have focussed or are focussing on oligos. If you wish to undertake some research and really want to arrive at an answer to your main question I would suggest that you start with the Pubmed website: <http://www.ncbi.nlm.nih.gov/pubmed/> and enter the search term "anaplastic oligodendrogliomas" (without the quotation marks). It will generate 3,763 citations. You will then need to browse the citations looking for authors and centres that appear to have frequent entries. That will narrow down the field and provide clues of names and locations.

Bear in mind that even though you are in North America the relevant expertise might be found somewhere in Europe or Japan, or elsewhere in the world.

Another resource to search is the clinical trials website: www.clinicaltrials.gov If you enter "anaplastic oligodendroglioma" you will generate 226 references but some of the trials listed there will be closed or completed. Those results can help you prioritise the results of the PUBMED search.

Eventually you will end up with a short list of ten or so researchers or centres. Try and ensure they are involved in current research, not research undertaken ten or fifteen years ago.

If you do not have access to the full text of what appear to be important articles, email the principal author seeking a copy and explaining your reason. Most authors will oblige and send an electronic copy and they might also point you in the direction of a fellow researcher or relevant studies that have not yet been reported in the literature. Many, however, do not have the time to engage in protracted communications.

Having said all of the above, I am familiar with the Xxxxxxx Hospital and they are among the best brain tumour resources in the world. I am sure your daughter's oncologist would already have an indication of who might be undertaking research in this area so you should enter into partnership with them by telling them that you intend to research internationally. For example, you might identify a trial or a project that appears to have promising results but your daughter's oncologist might be aware of something not apparent to you that reduces its potential efficacy or reliability.

There are at least 120 different types of brain tumour and most centres will only offer what has been identified as the appropriate "standard of care", of which you are obviously aware. They cannot offer access at their centre to every promising therapy or current trial for every type of brain tumour.

I wish you all the best with your enquiries.

Kind regards

Response from the enquirer:

From: xxxxxxxxxx **To:** chair@theibta.org
Subject: Re: Anaplastic Oligodendroglioma **Sent:** Monday, 2 January 2012 13:52 PM

Thank-you so much for your detailed response. Your research tips/guidance are much appreciated.