

## THE RARE CANCER NETWORK: ACCOMPLISHMENTS AND CONTINUING RESEARCH

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**Background:** In an era of evidence based medical decision making, the study of rare cancers presents a significant challenge. By definition, the study of adult rare malignancies is complicated by the difficulty of performing prospective trials on disease entities that occur so infrequently. Population based registry studies of rare cancers can provide greater statistical power than studies performed by individual institutions or institutional networks, but they often lack treatment specific data that would allow an analysis of the impact of individual treatment modalities.

**Purpose:** The Rare Cancer Network (RCN) was founded in 1993 in order to provide a multi-institutional framework to facilitate rare malignancy research, with a focus on the specific role of radiation therapy, through pooled data analysis by participating academic medical centers.

**Materials:** The RCN consists of a voluntary network of 130 investigators in 24 nations ([www.rarecancer.net](http://www.rarecancer.net)). Membership is open to any clinical investigator who is interested in open collaboration with the RCN. Topics of rare cancer research are proposed by individual researchers and the RCN coordinating office surveys the membership for their level of interest. Data is abstracted from existing cases and pooled through electronic means for analysis by the study primary investigator.

**Results:** 40 studies have been completed in the last 16 years, accruing over 3,500 patients, resulting in 25 peer reviewed publications to date. The median study size was 81 patients (range 9 to 443). Nine studies currently remain open for case accrual, including studies on adenosquamous carcinoma of the head and neck, primary hepatic lymphatic, primary bone lymphoma, mucosal Kaposi sarcoma, Rosai-Dorfman disease, glomus tumors or paragangliomas, thyroid lymphoma, adenoid cystic carcinoma of the lacrimal gland, and a case-control study in radiation-induced esophageal cancer.

**Conclusions:** The RCN has produced data better characterizing the treatment of select rare malignancies with radiotherapy. The involvement of new investigators from the Asian Pacific region in new and in ongoing studies is encouraged.

Select studies of interest	PI	# patients	Reference
Desmoid tumors	Baumert	110	Radiation Oncology 2007, 2:12
Orbital lymphoma	Martinet	90	Int J Radiat Oncol Biol Phys. 2003 Mar 15;55 (4):892-8.
Anal canal adenocarcinoma	Belkacemi	82	Int J Radiat Oncol Biol Phys. 2003 Aug 1;56(5):1274-83
Plasmacytoma	Knobel	258	Int J Radiat Oncol Biol Phys. 2006 Jan 1;64(1):210-7
Epidural lymphoma	Mirimanoff	48	Int. J. Rad. Oncol.Biol. Phys. 2006 Jul 1;65(3):817-23.
Radiotherapy in uterine papillary serous carcinoma	Goldberg	138	Gynecol Oncol. 2008 Feb;108(2):298-305
Phylloides tumors of the breast	Belkacemi	443	Int. J. Rad. Oncol.Biol. Phys. 2008; 70(2):492 - 500
Sarcomas of the breast	Bousquet	103	Radiother Oncol. 2007; 85(3):355 - 361
Small cell carcinoma of the prostate	Stein	30	The Am J Med Sciences 2008 336(6): 478-488
DCIS in patients younger than 45 years	Omlin	373	Lancet Oncology 7(8):652-6, 2006
Pediatric nasopharyngeal carcinoma	Ozyar	165	Radiotherapy&Oncology 2006 Oct;81 (1):39-46.
Cerebellar GBM	Weber	45	Int J Radiat Oncol Biol Phys. 2006 Sep 1, 66(1), 179-186
Radiotherapy in Erdheim-Chester disease	Miller	9	Radiotherapy & Oncology Volume 80, Issue 3 , September 2006, 323-326
Spinal myxopapillary ependymoma	Villa	85	Int J Radiat Oncol Biol Phys. 2009 Jul 15;74(4):1114-20.