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). 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.