

Resources for Carcinoid and NET Cancer Insurance Appeals

in

- [cancer insurance appeals](#)
- [carcinoid](#)
- [insurance appeals](#)
- [neuroendocrine tumors](#)

The Carcinoid Cancer Foundation is pleased to introduce this new section on our website to assist the carcinoid/NET community when appealing denied insurance claims. This section will serve as a repository for articles and other materials that have been used in appeals. We will build this resource list over time and invite you to submit articles through the Contact Us form on our site. We welcome your suggestions on how to make this section of the greatest value to the carcinoid/NET community.

HMO Coverage for Out-of-Network NETs Medical Care

Special thanks to Julie Portelli for sharing this extremely helpful information about her appeal when denied HMO coverage for out-of-state, out-of-network surgery at a Neuroendocrine Tumor Center. Julie says the foundation of her appeal was to know the “rules” by which the insurer is playing. “The rule book is the legal contract we enter into when we pay our premiums. My HMO insurer calls it an ‘Evidence of Coverage (EOC) contract.’ It tells us all in our contract what our rights are,” explains Julie. “Most insurers declare in their EOC that if they cannot provide ‘an appropriately qualified medical professional for your condition’ they will authorize a consultation with a Non-Plan Physician.” According to Julie, this critical piece of information “saved – or prolonged my life.” To read more details of Julie’s story, [CLICK HERE](#).

PPRT Insurance Coverage

[PRRTInfo.org](#) is an excellent website for information about PPRT treatments in Bad Berka, Germany. [CLICK HERE](#) for the page, **Working with Your Insurance**.

The authors of the website note: Some patients have been successful in seeking reimbursement for PPRT treatment and follow up. The process varies greatly based on your insurance company and if your policy is offered by the insurance company directly or if the insurance company manages the policy for the company you work for as a "self-insured policy."

An extremely valuable resource on this page is the opportunity to contact the website authors for a list of those who have successfully navigated with their insurance company and have been able to receive coverage.

Pump for Octreotide

Clinical Value of Monitoring Plasma Octreotide Levels During Chronic Octreotide Long-Acting Repeatable Therapy in Carcinoid Patients ([click here for full text](#))

Effect of Octreotide Dose and Weight on Octreotide Blood Levels in Patients With Neuroendocrine Tumors ([click here for full text](#))

Prospective Trial on the Effect of BMI and Sex on Octreotide Levels in Patients Undergoing Long-Term Octreotide LAR Therapy ([click here for full text](#))

A Discussion on the Utility of Various Routes of Administration of Octreotide Acetate ([click here for full text](#))

Rare Disease/Orphan Disease Designation for Carcinoid/NETs

For some appeals it may be helpful to refer to carcinoid/NETs as rare diseases/orphan diseases. Listed below is the definition of rare diseases in the United States with citations from the FDA (Food and Drug Administration) and NIH (National Institutes of Health).

The [Orphan Drug Designation program](#) provides orphan status to drugs and biologics which are defined as those intended for the safe and effective treatment, diagnosis or prevention of rare diseases/disorders that affect fewer than 200,000 people in the U.S., or that affect more than 200,000 persons but are not expected to recover the costs of developing and marketing a treatment drug. [This citation](#) is from the U.S. Food and Drug Administration (FDA).

Carcinoid and other neuroendocrine tumors, such as pheochromocytoma and pancreatic islet cell tumors, are listed on the NIH (National Institutes of Health) website under rare diseases. [Click here](#) for a list of rare diseases and more information.

[The Rare Diseases Act of 2002](#) and the [Orphan Drug Act](#) both define a rare disease.

Scans

This page from the Arkansas BlueCross BlueShield Coverage Policy Manual (Category: Radiology, Last Review: October 2012) is dedicated to [PET or PET/CT for Neuroendocrine Tumors](#). It mentions the newer analogue DOTATOC in the final paragraph.

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