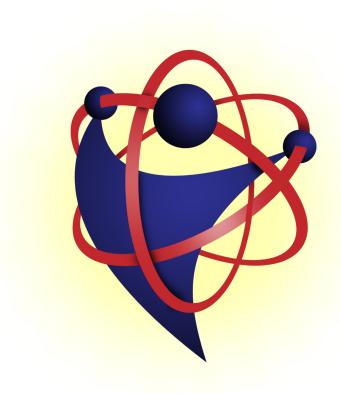


Patient Education for Those Seeking Peptide Receptor Radionuclide Therapy (PRRT) Josh Mailman, President NorCal CarciNET Community – Oakland CA



PRRTINFO.ORG BY PATIENTS • FOR PATIENTS

Background

Neuroendocrine Tumors (NETs) have an incidence of 5.25/100,000 in North America¹. Diagnostic and treatment choices have evolved over the last two decades to include molecular imaging and therapies. In the last decade Peptide Receptor Radionuclide Therapy (PRRT) has become more commonplace in the management of NETs in Europe but its use is still in its infancy in North America. In 2011, a website was launched in English that focused exclusively on PRRT. Visitors from around the world have made the website a destination for patient centered information on PRRT treatment and Gallium 68 (Ga68) imaging.

Results

30,000 visits and 15,000 searches² were analyzed to better understand the type of information patients are looking for when considering PRRT.

Rank	In Site Search Term ³	Rank	Article ³
1	Treatment	1	Restaging / Follow on Treatment
2	PRRT		1st World Congress on Ga-68 and Peptide
3	Ga68	2	Receptor Radionuclide Therapy
4	NETS		Audio and Video Recordings From 1st World
5	Patient	3	Congress
6	Imaging	4	FAQs
7	Theranostics		Zentralklinik Bad Berka Named ENETS
8	Individualized	5	Center of Excellence
9	Neuroendocrine		First World Congress of Ga-68 and PRRNT -
10	Scan	6	an Overwhelming Success
11	Medical Center	7	Centers that offer PRRT
12	Lymphoma	8	What are the Risk and Side Effects of PRRT
13	Neuroblastoma	9	PRRT Results
14	OSCAN	10	Who Should Consider PRRT
15	Renal		SNM 2012 Image of the Year: Bi-213-
16	Octreotide	11	DOTATOC for a New Treatment for GEP-NET
17	ENETS	12	Bad Berka Approach to PRRT
18	Risk	13	Multicenter PRRT Clinical Trial Announced
19	Gastrin	14	What is PRRT?
20	Digital recorder	15	Information for Referring Physicians

Methods

The website collects de-identified data on article selection, external web search and in site searches. Using this data we will try to understand what patients are interested in regarding molecular therapies and imaging for NETs.



Country / Territory	%
United States	56.2
India	4.7
United Kingdom	4.6
Canada	3.7
Germany	3.5
Japan	2.4
Australia	2.0
France	1.9
Italy	1.3
Singapore	1.1
Other	18.7

External Search Terms	%
Prrt	14
Bad Berka Zentralklinik	4
Prrtinfo.Org	4
Prrt Therapy	4
Prrt Treatment	4
Bad Berka	2
Prrt.Org	1
Prrt Bad Berka	1
Prrt Treatment Nets	1
What Is Prrt	1

Font size Bigger Reset Smaller
Search...
Search...

You are here: Home

Home	PRRTInfo.org - A Resource for Patients Considering PRRT Treatment.		
PRRT	Welcome to PRRTinfo.org		
Zentralklinik Bad Berka			
Patient Info			
Patient Stories	PRRTinfo.org is a site for patients considering PRRT (Peptide Receptor Radionuclide Therapy) treatment in Germany written by patients for patients. While much of this information can be used by patients seeking treatment at any PRRT Center worldwide, this site focus is on the treatment as provided by Dr. Richard Baum and his team at the Zentralklinik Bad Berka in Bad Berka, Germany. We also provide links to a select number of other medical centers that offer PRRT which can be found here .		
For Doctors			
PRRT News			
Resources / Links			
Presentations / PDFs	As with any site that offers information on treatment or travel, please confirm medical information with your medical team, as		
Calendar of Events	well as any travel information with the travel providers. We look forward to your feedback. IAEA Guidance on PRRNT for NETS		
Journey in Pictures			
FAQs			
About this site			
E Login	A committee of international experts under the auspices of the International Atomic Energy Agency (IAEA), in cooperation with the EANM Therapy, Oncology and Dosimetry Committees and with the Society of Nuclear Medicine and Molecular Imaging,		
Site Map			
	worked together to create this guidance document on the use of somatostatin analogue-based PRRNT. This 120 page		
Latest News (click to open) +	guidance document released in February 2013, was compiled taking into account recent literature and experts' opinion and can be downloaded here . An summary of the guide was also published in the European Journal of Nuclear Medicine and Molecular Imaging.		
Key Words (click to open) +	The authors of this international guide are: John J. Zaknun, L. Bodei, J. Mueller-Brand, M. E. Pavel, R. P. Baum, D. Hörsch, M. S		

¹ Yao JC, Hassan M, Phan A, et al. One hundred years after "carcinoid": epidemiology of and prognostic factors for neuroendocrine tumors in 36,825 cases in the United States. J Clin Oncol. 2008; 26:3063-3072.
 ² Data range 10/2011-10/2013.

³ Minimum of 1,500 in site search or article views.

Conclusions

With over 1,600 unique visitors monthly to a website dedicate to PRRT information, it is clear that patient, caregivers and other medical professionals are interested in PRRT. Centers providing this type of treatment should be offering their patient community detailed information about PRRT, how it is administered and its risks and side effects.

