



VHL Family Alliance Twitter Chat



2 new Tweets



[18h](#) [Einstein Coll of Med](#) [@EinsteinMed](#)

Thanks for the RTs, Mentions [@ACPSEM](#) [@BevtekSolutions](#) [@HrMervin](#) [@MontefioreNews](#) [@SpitzStrategy](#) [@pseudoknot](#) [@napernurse](#) [@ingridktw](#)

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Dr. Libutti explains what Neuroendocrine tumors are in less than 30 seconds [bit.ly/NeTs1](#) [#Video](#) [#NETs](#)

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[#Video](#): What should you do if you see someone having a [#heart](#) attack? Dr. Michler quickly explains: [bit.ly/aDrM4](#) [#Heartmonth](#)

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[#Heart](#) PT Julia Arcadipane shares how our medical/nursing staff went above & beyond to provide a personal touch [bit.ly/w2UfE3](#)

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[19h](#) [Norwood News](#) [@NorwoodNews](#)

Check out inspiring photos of young [#Bronx](#) heart patients playing their hearts out at a Montefiore reunion party. [ow.ly/9naWp](#)

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19h  [Montefiore Medical](#) [@MontefioreNews](#)

[#Kidney](#) damage can greatly increase the death rate in those w/ [#diabetes](#). Dr. Zonszein comments:
bit.ly/zPxyLo

20h  [CarcinoidCancer CCF](#) [@CarcinoidNETs](#)

[@min svart ros](#) Thank you so much for participating in the [@MontefioreNews](#) [#Monte NETs](#) chat today.
You are a terrific advocate & supporter!

Retweeted by [Montefiore Medical](#)

21h  [Montefiore Medical](#) [@MontefioreNews](#)

Short [#video](#) of Dr. [@SLibutti](#) discussing clinical trials @ [#Montefiore](#) [@EinsteinMed](#) Ctr for [#Cancer](#)
Care bit.ly/wfmXM5 [#Monte NETs](#)

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For more questions/information contact me on Twitter [@SLibutti](#). I will do my best to respond ASAP
[#Monte NETs](#)

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[@JennyBlue78](#) Dr. Chabot is outstanding! Great surgeon, ok squash player...you can tell him I said that -
[@SLibutti](#) [#Monte NETs](#)

[In reply to Jennifer Behnke](#)

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For a full list of resources provided by our moderators, please visit our page: bit.ly/ybdC8G [#Monte NETs](#)



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SPECIAL thanks to our moderators, [@CarcinoidNETs](#) [@Carcinoidaware](#) & [@VHLFA](#)! You all did a great job! -[@SLibutti](#) [#Monte NETs](#)



21h [Montefiore Medical](#) [@MontefioreNews](#)

That concludes our chat for the day! Thank you to all those who have participated -[@SLibutti](#) [#Monte NETs](#)



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Q23 Other benefits: close follow-up, experts involved in care & knowing you are helping make progress in dvlping new treatmnts [#Monte NETs](#)



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Q23 Benefits of being in a trial are access to treatments that you might not otherwise have available to you -[@SLibutti](#) [#Monte NETs](#)



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RT [@CarcinoidNETs](#): Q23 23) What are the benefits of being in a clinical trial? [#Monte NETs](#)



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Thank you for all of the work the alliance does on behalf of VHL patients! [@VHLFA](#) [#Monte NETs](#)

[In reply to VHL Family Alliance](#)



21h [Montefiore Medical](#) [@MontefioreNews](#)

RT [@VHLFA](#) All of the [#vhl](#) pts polled send you a big THANK YOU for all the wonderful work you have done on pancreatic NETs [#Monte NETs](#)



21h [Montefiore Medical](#) [@MontefioreNews](#)

Q21 Patients w/carcinoid syndrome should be evaluated for valvular heart disease -[@SLibutti](#)
[#Monte NETs](#)



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Q21 CV disease, diabetes & other cancers common in the general population are also seen in NET patients -
[@SLibutti](#) [#Monte NETs](#)



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Q20 Same is true for pts following panc. [#surgery](#). I always recommend consult w/a reg. dietitian who has experience w/NETs [#Monte NETs](#)



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Q20 For patients w/carcinoid syndrome, there are some dietary recommendations that can be very helpful -
[@SLibutti](#) [#Monte NETs](#)



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RT [@VHLFA](#): 20) If I have a NET cancer, what diet should I follow? [#vhl](#) [#pancreas](#) [#Monte NETs](#)



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[#Video](#): Dr. Libutti quickly discusses the risk factors influencing the dvlpmnt of [#NETs](#) [bit.ly/NeTs33](#)
[#Cancer](#) [#Monte NETs](#)

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Q22 Keep informed and be an advocate for your own health. -[@SLibutti](#) [#Monte NETs](#)



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RT [@CarcinoidNETs](#): Q22 What is the one thing we can do as patients to make the most impact on our health? [#Monte NETs](#)



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[@nevesmommy](#) Yes, a CD w/scans & report can be sent to Dr.Steven Libutti @ 3400 Bainbridge Ave, MAP4, Bronx, NY 10467 [#Monte NETs](#)

[In reply to Jody Di Trolio](#)



21h [Montefiore Medical](#) [@MontefioreNews](#)

[@fanthagi](#) Yes it is possible to have only a single carcinoid. -[@SLibutti](#) [#Monte NETs](#)

[In reply to Ramona hoogeveen](#)



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RT [@fanthagi](#): is there a possibility to only have One carcinoid polyp and nothing more or have they search on more places? [#Monte NETs](#)



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Q21 Patients w/carcinoid syndrome should be evaluated for valvular heart disease. -[@SLibutti](#) [#Monte NETs](#)



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Q21 CV disease, diabetes & other cancers common in the general population are also seen in NET patients [@SLibutti](#) [#Monte NETs](#)



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Q21 NET patients should not forget to be vigilant about other more common health problems that affect everyone - [@SLibutti](#) [#Monte NETs](#)



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RT [@Carcinoidaware](#) Q21 Are there other health concerns for NET cancer patients? [#Monte NETs](#)



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[@VHLFA](#) No, not necessarily. Non-functional [#NETs](#) can spread to other sites. Most commonly, [#liver](#) - [@SLibutti](#) [#Monte NETs](#)

[In reply to VHL Family Alliance](#)



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RT [@VHLFA](#): If a NET is not “producing,” does that mean it’s okay? [#pheo](#) [#pancreas](#) [#vhl](#) [#Monte NETs](#)



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Q19 Not necessarily. If carcinoid is in midgut & doesn't spread to liver, unlikely you'll develop carcinoid syndrome [@SLibutti](#) [#Monte NETs](#)



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RT [@CarcinoidNETs](#): Q19 If I have carcinoid, will I also have carcinoid syndrome? [#Monte NETs](#)



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[@VHLFA](#) Reg. therapies like isolated hepatic perfusion & RFA for PNET mets to liver effective & available: bit.ly/zX9Qrg [#Monte NETs](#)

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Q18 Since [#NETs](#) tend to be slow-growing tumors, if had surgery for 1 we will follow you for [@least](#) 10 yrs -[@SLibutti](#) [#Monte NETs](#)

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RT [@Carcinoidaware](#): Q18 How long do I have to be followed if I have no signs of cancer? [#Monte NETs](#)

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[@VHLFA](#) Yes, 2 new agents have recently been approved by [@FDA Drug Info](#) for metastatic PNETs, everolimus & sunitinib -[@SLibutti](#) [#Monte NETs](#)

[In reply to VHL Family Alliance](#)

21h  [Montefiore Medical](#) [@MontefioreNews](#)

RT [@VHLFA](#): Are there good targeted therapies for pancreatic NETs? [#vhl](#) [#pancreas](#) [#Monte NETs](#)

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Q16 But not every patient would be a good candidate for regional or targeted therapies [@SLibutti](#) [#Monte NETs](#)

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Q16 Regional or targeted therapies deliver therapies directly to the tumor & can avoid systemic toxicity -[@SLibutti](#) [#Monte NETs](#)

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Q16 Systemic therapies will get to multiple areas of the body where tumor cells may be present, but they can cause toxicity [#Monte NETs](#)



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RT [@CarcinoidNETs](#): Q16 Pros and cons of systemic vs. targeted therapies? [#Monte NETs](#)



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Be in the know, learn the signs & symptoms of [#NETs](#) from Dr. [@SLibutti](#) bit.ly/NeTs44 Short [VID]
[#Monte NETs](#)

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[@min svart ros](#) Can't do a complete eval ovr chat, pls feel free to contact me directly @ 718-862-8840 -
[@SLibutti](#) [#Monte NETs](#)

[In reply to danidawn](#)



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Q14 It's unusual for my pts to have significant complications once they go home requiring re-admissions to the hospital [#Monte NETs](#)



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Q14 I perform a pylorus preserving version of this operation for most vHL patients who need it. -[@SLibutti](#)
[#Monte NETs](#)



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Q14 In my experience "Whipple surgery", or pancreaticoduodenectomy, for PNETs seen in [#VHL](#) is very well tolerated -[@SLibutti](#) [#Monte NETs](#)



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RT [@VHLFA](#): 14) Many pts who undergo Whipple surgeries have post-op complications. Are there any alternatives? [#vhl](#) [#pancreas](#) [#Monte NETs](#)



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[@CardSharkMedia](#) Dr. Anton Bilchik is an excellent surgeon. [#Monte NETs](#)

[In reply to Steve Miller](#)



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[@min_svalt_ros](#) What dose of sando are you on? -[@SLibutti](#) [#Monte NETs](#)

[In reply to danidawn](#)



21h [danidawn](#) [@min_svalt_ros](#)

[@MontefioreNews](#) lung primary 2.5cm removed in 06. Have active syndrome since no tumors to be seen on sando need advice [@SLibutti](#) [#Monte NETs](#)

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21h [Bob W](#) [@Carcinoidaware](#)

Dr. Wolin will speak- 20 Experts, 500 patients- National NET Patient Conference- Register here tinyurl.com/7jdam4n [#Monte NETs](#)

Retweeted by [Montefiore Medical](#)



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[@VHLFA](#) RFA is a good technique for kidney lesions. Little to no experience w/RFA for panc. -[@SLibutti](#) [#Monte NETs](#)



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RT [@VHLFA](#): Are there other minimally invasive techniques that are reasonable to consider? RFA? cryo? focused US? [#vhl](#) [#pancreas](#) [#Monte NETs](#)

[In reply to VHL Family Alliance](#)



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Q15 My bias would be to perform surgery for a PNET in vHL if resection criteria are met -[@SLibutti](#) [#Monte NETs](#)



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[@CardSharkMedia](#) Dr. Wolin is an expert in [#NETs](#) & an excellent resource [#Monte NETs](#)

[In reply to Steve Miller](#)



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RT [@nevesmommy](#): [@MontefioreNews](#) [@slibutti](#) [#Monte NETs](#) Thank you for your input! It means so much to us. [#VHL](#) [#Monte NETs](#)

[In reply to Jody Di Trolio](#)



21h [Montefiore Medical](#) [@MontefioreNews](#)

Q15 For pancreas, I don't think there is enough experience yet to know the risks & benefits of cyber knife - [@SLibutti](#) [#Monte NETs](#)



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Q15 I am not certain of the benefits of cyberknife for kidney tumors & I would defer to my urologist colleagues on that 1 [#Monte NETs](#)



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[@signyourwords](#) Yes, a glucagonoma PNET can cause elevated blood sugar. -[@SLibutti](#) [#Monte NETs](#)

[In reply to Lori DeVoe](#)



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[@nevesmommy](#) If cyst is communicating with panc. duct, it should not be drained percutaneously & it may be cause of pain [#Monte NETs](#)

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Q12 The goal for surgery can be to cure disease or to eliminate or improve symptoms -[@SLibutti](#) [#Monte NETs](#)



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RT [@Carcinoidaware](#): 12) What are the goals of surgery for NETs? [#Monte NETs](#)



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[@MisoHungry](#) Pts can have underline co-morbidities or can dvlp co-morb. from functional [#NETs](#) Ex: [#pheo](#) & [#hypertension](#) [@SLibutti](#) [#Monte NETs](#)

[In reply to Dr. Jennie Chen-ergy](#)



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RT [@MisoHungry](#): [#monte nets](#) are there co-morbid diseases in nets? [#Monte NETs](#)

[In reply to Dr. Jennie Chen-ergy](#)

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[@nevesmommy](#) A 2cm cyst unless it's blocking pan. duct, is unlikely to cause pain -[@SLibutti](#)
[#Monte NETs](#)

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Cysts can be drained endoscopically or percutaneously w/low risk of complications but can return.
[#Monte NETs](#)

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[@VHLFA](#) If surgery isn't an option due to location or # of tumors, try medical therapies, regional therapies & radiotherapies. [#Monte NETs](#)

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[@VHLFA](#) Surgical resection is primary method for treating [#NETs](#). -[@SLibutti](#) [#Monte NETs](#)

[In reply to VHL Family Alliance](#)

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[@nevesmommy](#) How large is largest cyst? -[@SLibutti](#) [#Monte NETs](#)

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[@nevesmommy](#) You can take up to 3 creon25 w/each meal. Also, cysts that press on intestines/stomach can cause pain -[@SLibutti](#) [#Monte NETs](#)

[In reply to Jody Di Trolio](#)

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RT [@VHLFA](#): 11) What treatment options are available to someone with a NET? [#vhl](#) [#pancreas](#) [#Monte NETs](#)

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Q7 If you do not have a familial syndrome, the risk to your children is likely small. [#Monte NETs](#)

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Q7 If NET is due to inherited syndrome (MEN1, vHL, MEN2, SDH, NF), children should have genetic testing to determine risk [#Monte NETs](#)

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RT [@Carcinoidaware](#): 7) Is it likely my children will have a NET cancer if I do? [#Monte NETs](#)

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[@nevesmommy](#) Suggest as a 1st step to try panc. enzyme supplements. -[@SLibutti](#) [#Monte NETs](#)

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[@nevesmommy](#) Cysts, especially when large or decreasing panc. enzyme production, can cause pain. -
[@SLibutti](#) [#Monte NETs](#)

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Q6 However, lung carcinoids are not caused by smoking. Their cause is not well understood. -[@SLibutti](#) [#Monte NETs](#)

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Q6 Smoking is a risk factor for adenocarcinoma of the lung. -[@SLibutti](#) [#Monte NETs](#)

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RT [@Carcinoidaware](#): 6) I've never smoked. Why would I get lung carcinoid? [#Monte NETs](#)

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[@nevesmommy](#) Pain is not often associated w/ [#VHL](#), PNET or [#PHEO](#). I would start by looking for another cause. Panc. cysts? [#Monte NETs](#)

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RT [@nevesmommy](#): [#VHL](#) patient. [#pancreas](#) NET & [#pheo](#). moderate - severe abdo pain. how do u treat this? [#Monte NETs](#) [@slibutti](#) [#Monte NETs](#)

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[@MisoHungry](#) Yes. For example, a PNET that produces insulin can cause hypoglycemia & confusion. -
[@SLibutti](#) [#Monte NETs](#)

[In reply to Dr. Jennie Chen-ergy](#)

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RT [@MisoHungry](#) Can these neuroendocrine tumors affect endocrine linked behaviors? [#Monte NETs](#)



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Q5 Is very variable & depends on the tissue of origin & the type of [#NET](#) -[@SLibutti](#) [#Monte NETs](#)



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Q5 Some NETs take yrs to spread, others much shorter, still others may never spread -[@SLibutti](#) [#Monte NETs](#)



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RT [@Carcinoidaware](#): 5) How long does it take for a NET cancer to spread? [#Monte NETs](#)



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[@VHLFA](#) Imaging is the main tool for diagnosing & following [#NETs](#) that are non functional. -[@SLibutti](#) [#Monte NETs](#)

[In reply to VHL Family Alliance](#)



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RT [@VHLFA](#): What if they are not producing proteins that can be tracked in the blood? [#vhl](#) [#pancreas](#) [#Monte NETs](#)



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In case you missed it, Dr.[@SLibutti](#) explains what Neuroendocrine tumors are in less than 30 seconds [bit.ly/NeTs1](#) [VID] [#Monte NETs](#)

[View video](#)



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[@MisoHungry](#) An active area of research is to identify more sensitive & specific markers allowing accurate blood tests for [#NETs](#) [#Monte NETs](#)

[In reply to Dr. Jennie Chen-ergy](#)

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RT [@MisoHungry](#) What are some ways to increase accuracy and speed of diagnosis? Dont want precious time to get away. [#Monte NETs](#)

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Q9 Dx depends on type of NET, symptoms, family history, & can be made by history, imaging, blood tests and biopsy -[@SLibutti](#) [#Monte NETs](#)

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9) How are NETs diagnosed? What if they are not "producing"? [#vhl](#) [#pancreas](#) [#monte nets](#)

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[@MisoHungry](#) Time until diagnosis varies, depending on symptoms & lvl of suspicion. -[@SLibutti](#) [#Monte NETs](#)

[In reply to Dr. Jennie Chen-ergy](#)

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RT [@MisoHungry](#): [@MontefioreNews](#) How quickly are each of these usually diagnosed? [#Monte NETs](#)

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Q3 Carcinoids are [#NETs](#) in stomach, intestines or lungs. NETs occur in pancreas, thyroid, adrenal glands & other tissues [#Monte NETs](#)



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RT [@Carcinoidaware](#): 3) Is carcinoid the only NET cancer? [#Monte NETs](#)



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[@SheCaveDweller](#) PNETs/Carcinoids on a spectrum of how aggressive they can be. Survival rates vary, but measured often in yrs [#Monte NETs](#)

[In reply to Dawn Marie](#)



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Q2 Symptoms of [#NETs](#) -- flushing, diarrhea or hypoglycemia & hypertension-- can be caused by more common diseases -[@SLibutti](#) [#Monte NETs](#)



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Q2 Pancreatic NETs can be confused w/ pancreatic adenocarcinoma -[@SLibutti](#) [#Monte NETs](#)



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Q2 GI carcinoids can be confused w/lymphomas, adenocarcinomas or benign bowel obstructions. -[@SLibutti](#) [#Monte NETs](#)



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RT [@Carcinoidaware](#): Q2 What other diseases are confused with NETs? [#Monte NETs](#)



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Q4 Pancreatic [#NETs](#) tend to be slower growing, w/lower mortality. -[@SLibutti](#) [#Monte NETs](#)



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Q4 Pan. [#NETs](#) can produce functional proteins that cause symptoms. Each NET originates from a different cell type -[@SLibutti](#) [#Monte NETs](#)



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Q4 Pancreatic adenocarcinomas don't produce functional proteins & have high mortality rate -[@SLibutti](#) [#Monte NETs](#)



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Q4 Most common form of pancreatic cancer is adenocarcinoma, a fast-growing, invasive cancer that often spreads -[@SLibutti](#) [#Monte NETs](#)



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RT [@VHLFA](#): Q4. What's the difference between pancreatic cancer and a pancreatic NET? [#vhl](#) [#pancreas](#) [#Monte NETs](#)



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Q1 Sometimes when these tumors form, they can produce functional proteins that have an effect on the body. -[@SLibutti](#) [#Monte NETs](#)



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RT [@CarcinoidNETs](#): Q1 What is a Neuroendocrine tumor? [#Monte NETs](#)



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Q1 [#NETs](#) are tumors that occur in specialized cells that exist in the endocrine organs and the nervous system. [@SLibutti](#) [#Monte NETs](#)



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Let's begin! [#Monte NETs](#)



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Our moderators for the chat will be the CCF [@CarcinoidNETs](#), VHL Family Alliance [@VHL Alliance](#) & CCAN [@CarcinoidAware](#) [#Monte NETs](#)



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Thank you all for joining us today! [#Monte NETs](#)



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A few more minutes until our [#Monte NETs](#) tweet chat! Who's already here?



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In 1hr (2pm EST), join us for our [#Monte NETs](#) chat to discuss Neuroendocrine Tumors w/expert Dr. [@SLibutti](#) [bit.ly/FEB29](#)



29 Feb [Montefiore Medical](#) [@MontefioreNews](#)

[VID] Neuroendocrine tumors are rare, but how rare are they? Ask Dr. Libutti [bit.ly/NeTs22](#) Join today's [#Monte NETs](#) chat @ 2pm EST

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29 Feb [Montefiore Medical](#) [@MontefioreNews](#)

[@shecavedweller](#) Yes it is, hope you can join us.

[In reply to Dawn Marie](#)



[29 Feb](#) [CarcinoidCancer CCF @CarcinoidNETs](#)

Today is [@rarediseaseday](#). Join the chat on [#carcinoid](#) and [#netcancer](#) at 2 pm, EST. Follow [@MontefioreNews](#) [#Monte NETs](#)

[@nevesmommy](#) Thanks for the kinds words about Dr. Libutti. We look forward to having you at our chat!