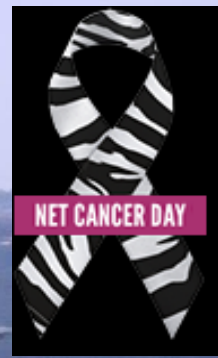




# World NEN Lives 2020 Congress

23-24 September 2020



## THE COMPLEX JOURNEY OF THE NEN PATIENT

*How to live with NEN as a Chronic Disease*

Simona Glasberg, MD

Neuroendocrine Tumor Unit, ENETS Center of Excellence  
Hadassah-Hebrew University Medical Center  
Jerusalem, Israel





# NEN Patient - Importance of Education... The Scenario

## NET Unit

.....One day, all of the sudden,  
a person is diagnosed  
as having a NEN.....

**Surprised**  
**Scared**  
**Frightened**

...What will happen to me?  
Will I be in pain?  
Is this treatable?  
Will I tolerate the treatment?  
What will happen with my family?  
How to tell my kids? My  
spouse? My friends?...

...Am I going to die?  
How long will I live?...





# Why Patient Education is Mandatory in NEN Patients?

NET Unit

- It gives mental, moral and spiritual support

• **Hope**

• Confidence

**"Fight NEN With Knowledge"**  
(understanding the disease)

• Freedom

• **Courage**

- It helps to face dangers and difficulties

- It helps to overcome weakness and fear



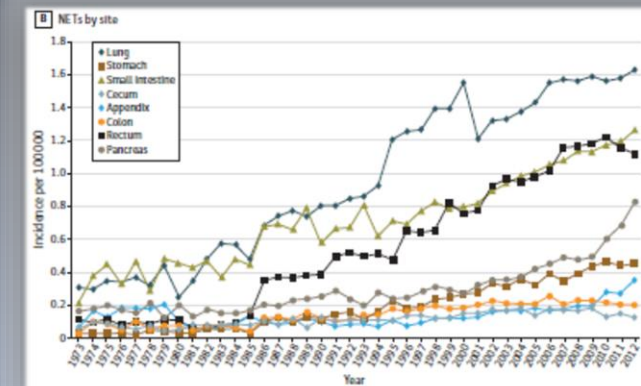
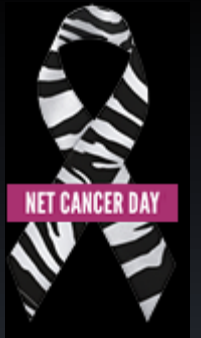
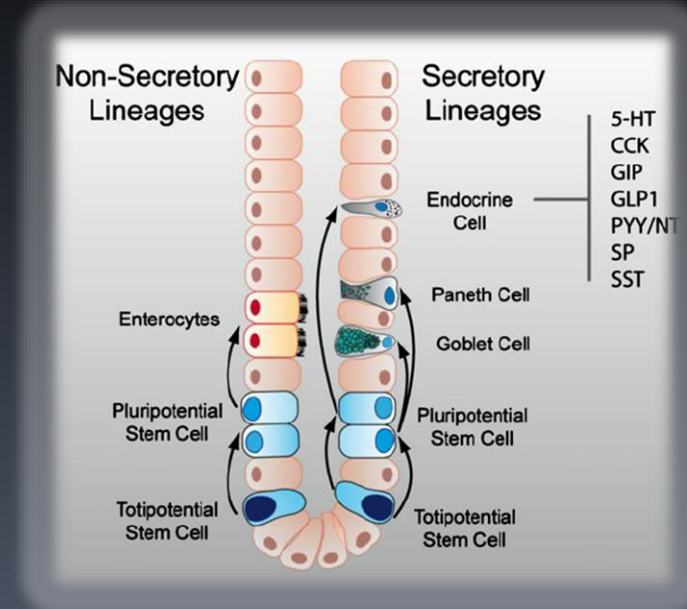
NET Unit



# Introduction: Many Challenges in NENs

- ❑ Heterogeneous
- ❑ Arise from NE cells throughout the body
- ❑ Increasing incidence ( ~ 6.9/100.000 people)
- ❑ Sporadic/ Hereditary (MEN/VHL/NF1/TSC)
- ❑ Majority, Well Differentiated G1 , G2 & G3
- ❑ Frequently (65%) metastatic at diagnosis
- ❑ 70% Non-functioning (30% Functioning)
- ❑ Variety of therapeutic options (need for dedicated MDT)

Dasari A. et al., JAMA Oncol, April 2017  
Pavel M. et al, ENETS Guidelines, Neuroendocrinology, 2016







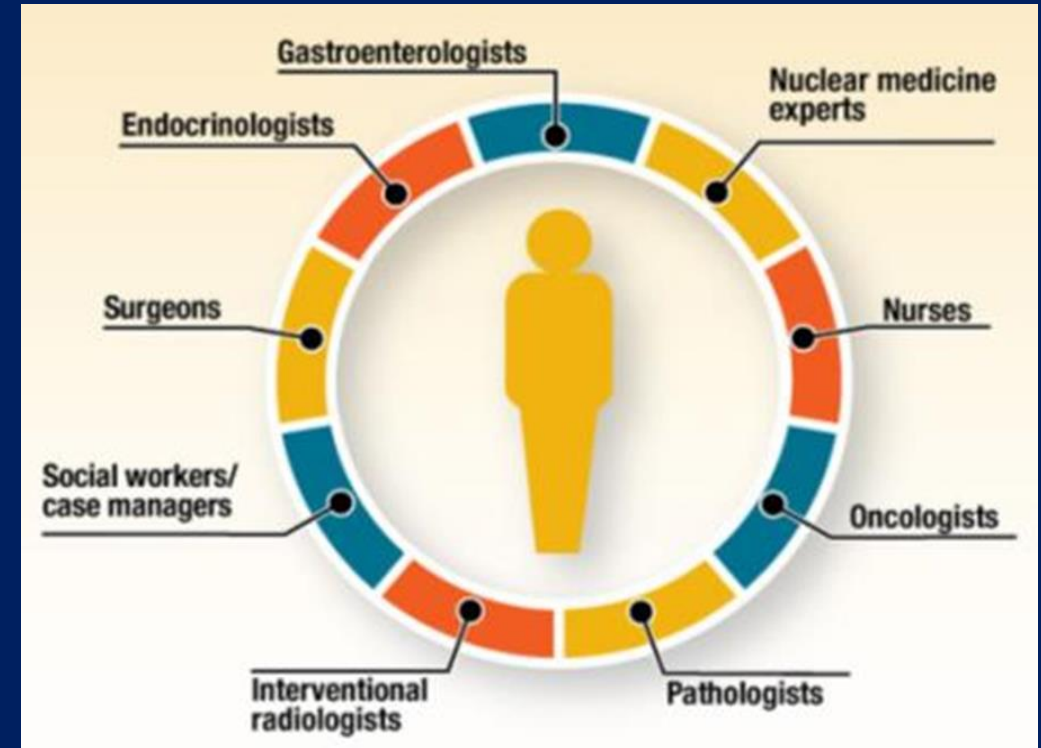
NET Unit



# Advantages of Using an MDT Approach to NENs Management



- ❑ Accurate diagnosis and staging
- ❑ Evaluation of performance status and quality of life
- ❑ Decide and Deliver therapy and information on the disease
- ❑ Continuous reassessment, discussion, and review of the individualized care plan
- ❑ Significantly improved survival compared with standard of care offered in non specialist facilities.

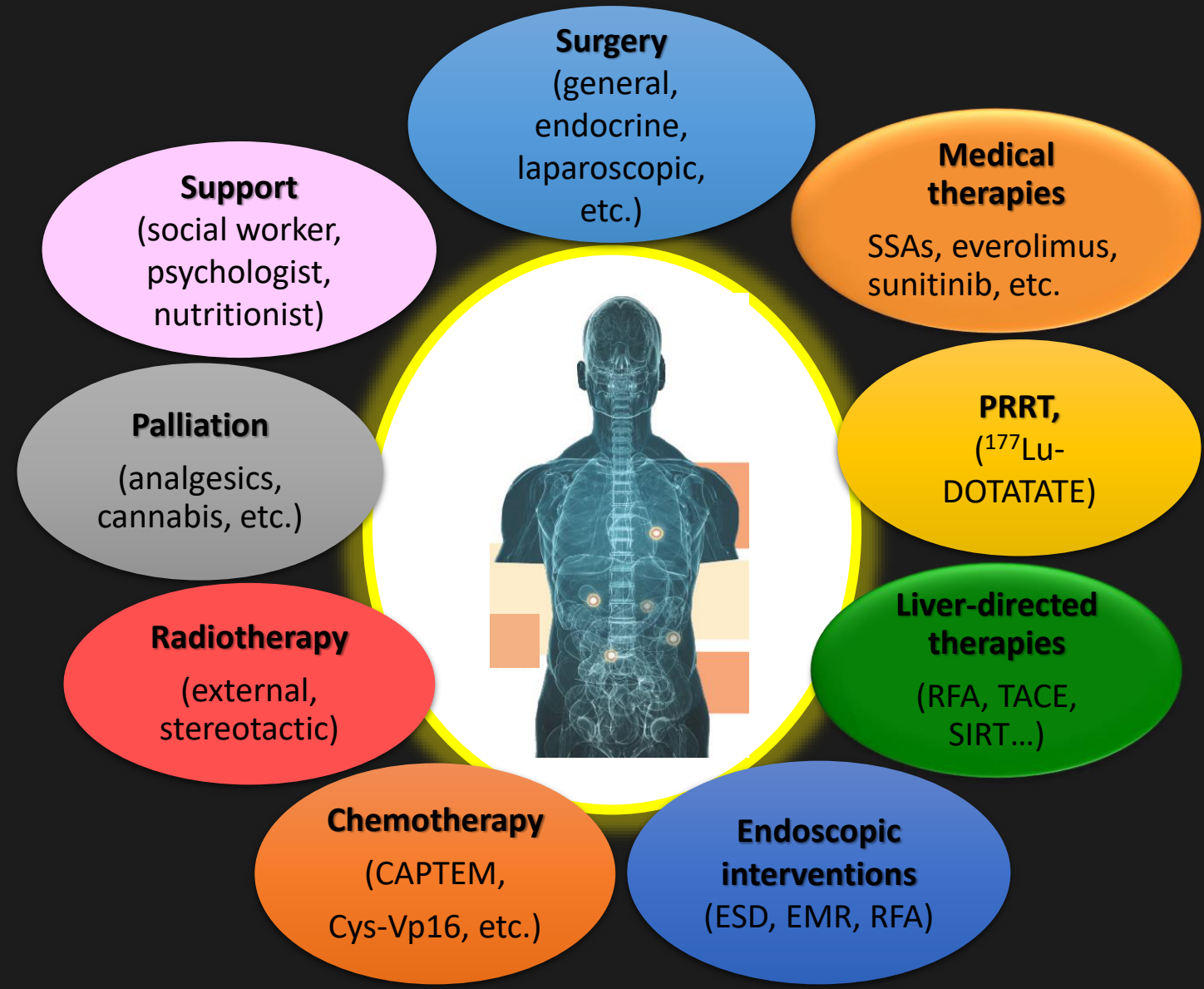




NET Unit



# Treatment Options, individualized





NET Unit



# Therapeutic Decision



- ❑ Type of NENs
- ❑ TNM stage & ENETs grade:G1, G2, G3 or G4
- ❑ Extent of liver involvement
- ❑ Functional status of the tumour
- ❑ Patient's performance status
- ❑ Availability of different therapeutic modalities



**Most patients  
receive a  
combination  
of treatment  
modalities.**



NET Unit



# Important Goals for Care-givers

William Osler: “The good physician treats the disease; the great physician treats the patient who has the disease...”

I would humbly add: “...*the ultimate physician treats the patient who has the disease but looks also beyond the individual patient, to deeply understand the illness and eventually to find cure ... or the best way to live with it...*”





VIRTUAL

# World NEN Lives 2020 Congress Program September 23–24, 2020

Co-Chair:  
**Michael Rosenberg**  
Founder MENETS, Israel  
MichaelR@menets.org



**MENETS**  
Middle East Neuroendocrine Tumor Society  
תחומה לרפואה אנדוקרינית ומערכת העיכול  
ממנה אורח חיים המענה לחיפה, ארצות  
www.MENETS.org

Co-Chair:  
**Simona Glasberg, MD**  
Director of the Neuroendocrine  
Tumor Unit, ENETS Center of  
Excellence, Hadassah, Jerusalem  
simonag@hadassah.org.il



**Hadassah**  
University  
Hospital  
Founded by Hadassah, the Women's Zionist Organization of America

ENETS Centers of Excellence  
**ENETS CoE**  
Achieving Quality since 2008

GMT +2	Wednesday, September 23, 2020 - SESSION I
13:00	Greetings: <b>Conference Co-Chairs: Michael Rosenberg, IL, Simona Glasberg, IL</b> Chair: <b>Simona Glasberg, IL</b>
13:15	Lectures: <b>Marianne Pavel, GER</b> <i>2020 STATE OF THE ART IN NENs DIAGNOSIS AND THERAPY</i>
13:35	<b>Rodney Hicks, AUS</b> <i>PRRT - WHICH PATIENTS SHOULD WE TREAT?</i>
13:50	<b>PRRT Patient, AUS</b> <i>LIFE WITH PRRT</i>
14:05	<b>Martyn Caplin, UK</b> <i>THE ROLE OF ENDOSCOPY IN NENs DIAGNOSIS AND TREATMENT</i>
14:20	<b>Nicola Fazio, IT</b> <i>CHEMO- / RADIO- THERAPY - WHICH PATIENTS SHOULD WE TREAT?</i>
14:35 - 15:00	Break

GMT +2	Wednesday, September 23, 2020 - SESSION II
15:00	Chair: <b>Simona Glasberg, IL</b> Lectures: <b>Simona Glasberg, IL</b> <i>FUNCTIONING NENs - CARCINOID SYNDROME AND CARCINOID HEART DISEASE</i>
15:15	<b>Rafi - Carcinoid Syndrome Patient, IL</b> <i>LIFE WITH CARCINOID SYNDROME</i>
15:30	<b>Orit Twitto, IL</b> <i>APPENDICINAL NENs - RIGHT HEMICOLECTOMY NEEDED?</i>
15:45	<b>Amit Tirosh, IL</b> <i>PANCREATIC NENs - FUNCTIONAL / NON-FUNCTIONAL MATTERS</i>
16:00	<b>Haggi Mazeh, IL</b> <i>PRACTICAL LESSONS FROM SURGICAL MANAGEMENT OF NENs</i>
16:15	<b>Ester Osher, IL</b> <i>LUNG NENs - MAINSTREAM IN DIAGNOSIS AND TREATMENT</i>
16:30	<b>Kira Oleinikov, IL</b> <i>TREATMENT OF PHEOCHROMOCYTOMA &amp; PARAGANGLIONOMA PATIENTS</i>
16:45	<b>Ofri Mosenzon, (IL)</b> <i>DIABETES MANAGEMENT OF NENs</i>
17:00	<b>Simona Glasberg, IL</b> <i>Closing: Day One</i>

GMT +2	Thursday, September 24, 2020 - SESSION I
	Chair: <b>Michael Rosenberg, IL</b>
13:00	Lectures: <b>Michael Rosenberg, IL</b> <i>INTENSIVE PERSONALIZED PROGRAM FOR DAILY LIVING WITH NENs AS A CHRONIC DISEASE</i>
13:20	<b>Ronny Allan, UK</b> <i>"PATIENTS INCLUDED" - A PATIENT LIFE PERSPECTIVE</i>
13:40	<b>Sheila Caudill, USA</b> <i>CARING FOR THE CARER</i>
14:00	<b>Catherine Bouvier, UK</b> <i>CARING FOR THE CARER</i>
14:20	<b>Ilanit Tal, (IL)</b> <i>NURSE PERSPECTIVE IN NEN PATIENTS CARE</i>
14:45	<b>Ronit Enderevelt, IL</b> <i>NENs NUTRITION BOOK - HEBREW, ARABIC, RUSSIAN</i>
15:00	<b>Tara Whyand, UK</b> <i>THE ROLE OF THE DIETITIAN IN NENs MANAGEMENT</i>
15:15 - 15:30	Break

GMT +2	Thursday, September 24, 2020 - SESSION II
	Chair: <b>Michael Rosenberg, IL, Simona Glasberg, IL</b>
15:30	Lectures: <b>Jon Strosberg, USA</b> <i>IMMUNOTHERAPY FOR NENs - WHEN AND HOW ?</i>
15:45	<b>Simron Singh, CND</b> <i>NENs CARE DURING AND BEYOND THE COVID-19 PANDEMIC</i>
16:00	<b>Patient Presentation, CND</b> <i>PATIENT CARE - NENs AND COVID -19</i>
16:15	<b>Rachel Riechelmann, BRA</b> <i>GENDER CONSIDERATION IN TREATMENT OF NENs PATIENTS</i>
16:30	<b>Jie Chen, CH</b> <i>DIFFERENCES AND SIMILARITIES BETWEEN NENs PATIENTS FROM DIFFERENT CONTINENTS - LESSONS FROM CHINESE PATIENTS</i>
16:45	<b>Emily Bergsland, USA</b> <i>GENETICS OF NENs - WHEN TO THINK OF IT</i>
17:00	<b>To be Confirmed</b> <i>CANNABIOIDS AND NENs</i>
17:15	<b>Simona Glasberg, (IL), Michael Rosenberg, (IL)</b> <i>CONFERENCE CLOSING REMARKS</i>