



**Sunday, September 29, 2024**  
**8:30am–3:30pm**

**UCSF Mission Bay Conference Center**  
1675 Owens Street, San Francisco, CA 94158

**2024**

# **Bay Area NET Patient Education Conference**

**Hosted By**



**UCSF** Helen Diller Family  
Comprehensive  
Cancer Center

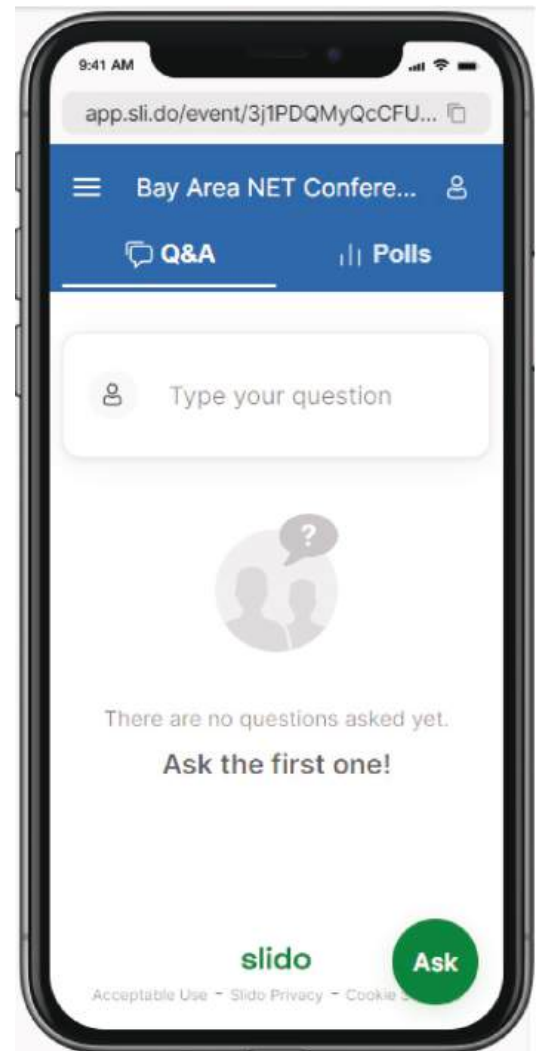
# Ask Questions Online through Sli.do!

1. On your phone, tablet or computer, join the free wifi at UCSFguest (or use your cellular network with normal data rates applying).
2. Open your web browser and go to [www.slido.com](http://www.slido.com), then enter our event code: **NETS**
3. Click the green Join Event button on the Welcome page (screen 1).

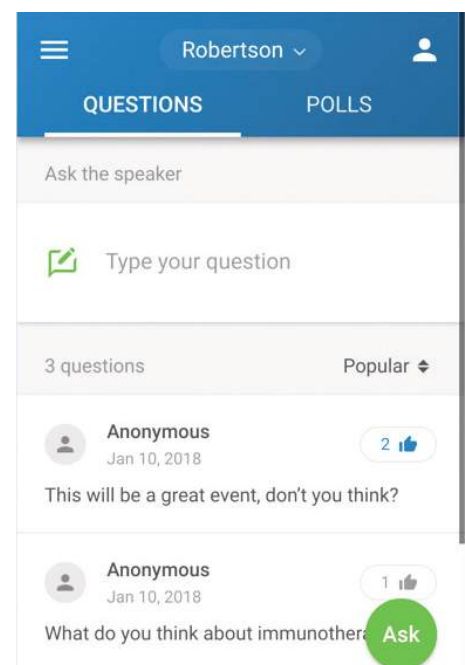
That's it! You are ready to ask questions or vote a question up (screen 2). There's no need to duplicate a question. To maintain your privacy please ask anonymously or use only your initials—no full names, please.

While we cannot guarantee your question will be addressed, questions with the highest numbers of votes stand a better chance of getting answered by the speaker.

Screen 1

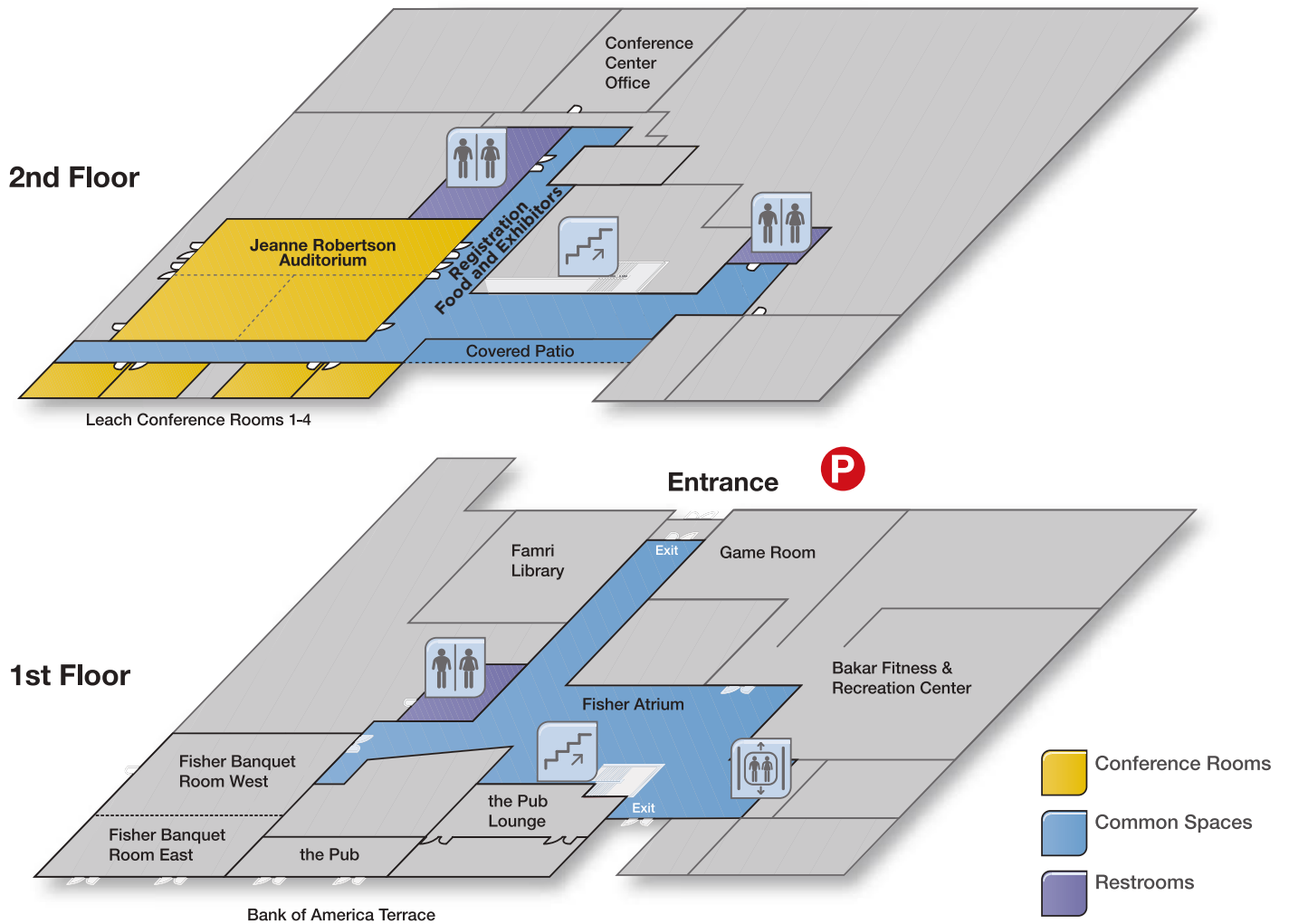


Screen 2



# Building Floor Plan

All Conference Activities will be on the 2nd floor.  
There are stairs and elevators to help you get to the conference floor.



# WELCOME

It is with great pleasure that we welcome you to the 2024 Bay Area Patient Education Day at UCSF. We have grown from the 90 participants who attended our first conference at UCSF in 2012 to nearly 400 people at our 2019 conference with hundreds more who joined us around the world via our web-cast. NorCal CarciNET Community is proud to co-host this event with Dr. Bergsland, Dr. Mulvey and the rest of the UCSF team in collaboration with Stanford Medicine and Kaiser Permanente.

In keeping with NorCal CarciNET's mission of providing education, support and hope, our day will be filled with talks, sessions and networking opportunities for patients, family members and friends.

**EDUCATION:** Dr. Emily Bergsland from UCSF will open the day with a Neuroendocrine Tumor (NET) overview to help newcomers and those who need a refresher to understand the disease and the diagnostic imaging tests that are used to monitor high and low grade NETs. Dr. Tom Hope will then review the current landscape for peptide receptor radionuclide therapy (PRRT) and Dr. Eric Nakakura will talk about the role of surgery for primary tumors and metastases in patients with NETs. Dr. Nicholas Fidelman will then provide an overview of the different types of liver-directed treatments (LDT), including an update on histotripsy. In the afternoon we'll host disease-specific breakouts for GI NETs, Pancreas NETs, Lung/thymic NETs, and high grade tumors (including well differentiated G3 NETs, and poorly differentiated neuroendocrine carcinomas-NECs), each led by faculty. Lastly we will host a tumor board to highlight how multidisciplinary teams integrate information to individualize care.

**SUPPORT:** During lunch Dr. Paul Lindenfeld will host a table aimed at providing information about palliative care and strategies for managing NET-related symptoms and/or treatment associated side effects. Dr. Myron Kwong will host a table for learning about resources at Kaiser Permanente for patients with NETs, while Angela Laffan, NP will be available to review general cancer wellness resources. Other tables will be staffed so attendees can learn more about PRRT, LDT, surgery, and integrative oncology. Attendees are encouraged to visit at least two tables during the 75-minute lunch session.

Our Caregiver Track will feature a breakout session entitled "caring for the caregiver" and another on cooking and nutrition for patients with NETs. There will also be a table during lunch focused on parenting when you or your partner has cancer. We would like to thank the educators from Cancer Support Community, UCSF, and XX are facilitating these activities.

**NETWORKING:** There will be several opportunities for networking throughout the day during breaks. In addition, during lunch, several tables will be set up for caregivers and patients for networking and discussing specific topics of interest. In addition to the tables focused on the topics described above, there will be tables for those with "early onsets NETs" (defined as a diagnosis at age <50) and for caregivers .

**HOPE:** During the day we will learn about what is on the horizon for patients with high and low grade NET/NEC. Several speakers will highlight the results from clinical trials and ongoing studies that aim to answer important questions in the field or investigate new therapeutic strategies.

This day of Education, Support and Hope would not be possible without the support of the many speakers, moderators and panel members from 3 Bay Area institutions plus 20 volunteers from the NorCal CarciNET Community and UCSF. We would also like those that provided education support grants and our industry support partners who are listed in this program. Please take the time to visit them in the Atrium on the first floor and our nonprofit supporters on the second floor. A special thanks to Kim Darin and Jennifor Morris of UCSF who helped coordinate this conference with NorCal CarciNET Community.

With gratitude,

**Josh Mailman**  
President, NorCal CarciNET Community

# AGENDA

TIME	SESSION	LOCATION
8:30	<b>Registration</b>	<b>Atrium</b>
8:50	<b>Introductions/Announcements</b> Mailman (NorCal CarciNET), Mulvey (UCSF)	<b>Robertson Auditorium</b>
9:00	<b>NET Basics: Types of NETS, Common Treatments, and What You Should Know About Your Tumor</b> Bergsland (UCSF), Moderator: Mailman (NorCal CarciNET)	<b>Robertson Auditorium</b>
9:30	<b>PRRT—Where Are We Now and What’s on the Horizon? Including Alpha and Beta, Along with Nuts and Bolts (Treatment Process, Radiation, Safety, Retreatment Long-Term Impact) (Moderator: Mailman (NorCal CarciNET)</b> Hope (UCSF), Moderator: Mailman (NorCal CarciNET)	<b>Robertson Auditorium</b>
10:05	<b>Break</b>	
10:20	<b>Surgery for NETs—Details Matter. The Type of Surgery and Impact of Patient and Tumor Characteristics</b> Nakakura (UCSF), Moderator: Mulvey (UCSF)	<b>Robertson Auditorium</b>
10:40	<b>Alphabet Soup—Liver Directed Therapy for NETs (TACE, TAE, SIRT, SBRT and Histotripsy)</b> Fidelman (UCSF), Moderator: Mulvey (UCSF)	<b>Robertson Auditorium</b>
11:05	<b>Recent Advances &amp; Ongoing Clinical Trials</b> Bergsland (UCSF)—Well Differentiated NETs Mulvey (UCSF)—Poorly Differentiated NEC	<b>Robertson Auditorium</b>
11:30	<b>Q &amp; A</b> All morning participants, Moderator: Mailman (NorCal CarciNET)	<b>Robertson Auditorium</b>
11:45	<b>Lunch &amp; Discussion Tables (See separate schedule on next page)</b>	
1:00	<b>Group 1A—GI NETs</b> Bergsland (UCSF), Chen (UCSF), Grady (Stanford), Fidelman (UCSF), Nakakura (UCSF), Vezeridis (Stanford)	<b>Robertson Auditorium</b>
	<b>Group 1B—Lung NETs</b> Fidelman (UCSF), Hope (UCSF), Hotca-Cho (UCSF), Mulvey (UCSF), Song (Stanford)	<b>Small Conference Room 1</b>
	<b>Group 1C—Caring for the Caregiver</b> Lindenfeld (UCSF), Linzer, Magee	<b>Small Conference Room 2</b>
1:35	<b>Break</b>	
1:45	<b>Group 2A—Pancreas NETs</b> Bergsland (UCSF), Fidelman (UCSF), Hotca-Cho (UCSF), Nakakura (UCSF), Song (Stanford), Vezeridis (Stanford)	<b>Robertson Auditorium</b>
	<b>Group 2B—High Grade NENs (G3NET and NEC)</b> Bergsland (UCSF), Chen (UCSF), Fidelman (UCSF), Grady (Stanford), Hope (UCSF), Mulvey (UCSF)	<b>Small Conference Room 1</b>
	<b>Group 2C—Cooking and Nutrition for Carcinoid</b> Macaire (UCSF)	<b>Small Conference Room 2</b>
2:20	<b>Break</b>	
2:30	<b>PANEL: Tumor Board</b> Moderator: Bergsland (UCSF), Chen (UCSF), Fidelman (UCSF), Grady (Stanford), Hope (UCSF), Kwong (Kaiser-San Jose), Mulvey (UCSF), Nakakura (UCSF), Song (Stanford), Vezeridis (Stanford)	<b>Robertson Auditorium</b>
3:10	<b>Wrap Up/Final Q &amp; A</b> Bergsland (UCSF), Mailman (NorCal CarciNET), Mulvey (UCSF)	<b>Robertson Auditorium/ Atrium</b>
3:30	<b>End</b>	

# LUNCH DISCUSSION TABLES

Try to change topics at least once in the 75 minutes (if not more). We will make an announcement at the 35-minute mark to indicate that we are at the half way point of lunch. Hopefully individuals can visit at least 2 tables during the lunch break.

All will be in Robertson Auditorium

TABLE	TOPIC
1	<b>Palliative Care and Symptom Management</b> Paul Lindenfeld, MD (UCSF) Carissa Cleverley-Valencia, RN (UCSF) Connie LI, NP (UCSF)
2	<b>Parenting When You or Your Partner Has Cancer</b> Juliette Linzer (NorCal CarciNET) Liz Magee (NorCal CarciNET)
3	<b>NETworking: Caregiver Table</b> Lisa Yen (LACNETS)
4	<b>NETworking: Early Onset NETs (for those diagnosed at age &lt;50)</b> Jessica Thompson (NETRF)
5	<b>NET Resources at Kaiser</b> Myron Kwong (Kaiser-San Jose)
6	<b>Cancer Wellness Resources</b> Angela Laffan (UCSF)
7	<b>External Radiation for NET and NEC—Including Radiation to Liver Tumors, Pancreas/Rectal Masses, Bone Metastases</b> Will Chen (UCSF) Alexandra Hotcha-Cho
8	<b>Preparing for/Recovering from NET Surgery</b> Eric Nakakura, MD, PhD (UCSF)
9	<b>Integrative Oncology -What Is It, and What are the Benefits for Patients with NETs?</b> Michael Lister, RN (UCSF)
10	<b>Identifying and Navigating Enrollment in Clinical Trials</b> Josh Mailman (NorCal CarciNET)
11	<b>PRRT Patient Experience</b> Erin Grady, MD (Stanford) Jerry Magee (NorCal CarciNET)
12	<b>PRRT Facts and Practical Aspects (Radiation Safety, etc)</b> Hong Song (Stanford) Cat Hoffman, NP (Stanford) Rebecca Mirro, RN (UCSF) Sheila Lindsay, NP (UCSF)
13	<b>Liver Embolization Facts and Practical Aspects</b> Nick Fidelman, MD (UCSF) Alex Vezeridis, MD, PhD (Stanford)

# SPEAKER BIOGRAPHIES

## **Emily Bergsland, MD**

### **Professor of Medicine, UCSF Helen Diller Family Comprehensive Cancer Center and Director of the UCSF Center for Neuroendocrine Tumors**

Dr. Bergsland holds the Ernest Rosenbaum, MD Endowed Chair in Medical Oncology and is the Associate Director for Education for the UCSF Helen Diller Family Comprehensive Cancer Center. Dr. Bergsland earned her medical degree from the University of Minnesota and completed training in internal medicine at UCSF. She subsequently completed a fellowship in Medical Oncology and a training program in Molecular Medicine before joining the UCSF faculty in 1998. Dr. Bergsland specializes in gastrointestinal oncology, with clinical care and research efforts focused on advancing outcomes in patients with neuroendocrine tumors. She is past-Chair of the Neuroendocrine Tumor Task Force of the National Cancer Institute (NCI) Gastrointestinal Steering Committee, past-president of the North American Neuroendocrine Tumor Society, and current Chair of the NCCN Neuroendocrine and Adrenal Tumor (NEAT) Guidelines Panel.

## **William Chen, MD**

### **Clinical Instructor in the Department of Radiation Oncology, UCSF**

Dr. Chen received his medical degree from UCSF, completed a one-year internship at Kaiser Permanente, San Francisco, and then completed residency in Radiation Oncology at UCSF. He currently treats patients with gastrointestinal malignancies, including neuroendocrine tumors, at UCSF.

## **Nicholas Fidelman, MD, FSIR**

### **Professor of Radiology and Biomedical Imaging, UCSF**

Dr. Nicholas Fidelman is a. Dr. Fidelman obtained his M.D. degree at UCSF in 2002, completed residency in Diagnostic Radiology in 2007, and fellowship in Vascular and Interventional Radiology at UCSF in 2008. Dr. Fidelman's clinical and research interests are in the area of liver tumor trans-arterial therapies including embolization, chemoembolization, and Yttrium-90 radioembolization.

## **Erin Grady, MD, CCD, FACNM, FSNMMI**

### **Clinical Professor of Radiology, Stanford Medicine**

Dr. Grady is nuclear medicine physician at Stanford Hospital and Clinics in Stanford, California. She is actively involved nationally in the SNMMI in multiple capacities including as a Director-at-Large on the SNMMI Board of Directors, chair of the Nuclear Medicine Program Directors, a member of the General Nuclear Medicine Council board, co-chair of the Government Relations Committee and a longstanding member of the Coding and Reimbursement Committee. In addition, she is a past chair of the American Board of Nuclear Medicine and has served on the board of appeals panel, review committee and milestone development committee for Nuclear Medicine and milestone revision committee for Nuclear Radiology at the ACGME. Her areas of research interest include quality, education, radiopharmaceutical therapy and finding answers to clinical questions that arise during the course of practice. She is passionate about education in nuclear medicine, nuclear medicine's future and is a staunch advocate for patients.

## **Catiussi Hoffmann, NP**

### **Nurse Practitioner, Theragnostics Clinic, Stanford Medicine**

Catiussi Hoffman assists patients in the preparation for radionuclide therapies and the management of their side effects. One of these radionuclide therapies is known as Peptide Receptor Radionuclide Therapy (PRRT) which is typically given for patients with neuroendocrine tumors (NETs). Cat is dedicated to supporting patients and families in their theragnostic journeys and takes pride in providing patients the most excellent care while optimizing their quality of life during their radionuclide therapies. She has earned her master's degree from University of San Francisco as a clinical nurse leader and completed her post-master's program as family nurse practitioner at San Francisco State University. Cat joined the department of Radiology at Stanford in 2017 and has been with the Nuclear Medicine, Theragnostics Team since 2020.

## **Thomas Hope, MD**

### **Professor in Residence, Abdominal Imaging and Nuclear Medicine, UCSF and the San Francisco Veterans Affairs Medical Center**

Dr. Hope is a Professor in Residence in the Abdominal Imaging and Nuclear Medicine sections at UCSF and the San Francisco Veterans Affairs Medical Center. In 2007, he received his medical degree from Stanford University. He attended the School of Medicine and completed a one-year internship at Kaiser Permanente in San Francisco. From 2008 to 2012, Dr. Hope completed a residency in diagnostic radiology at UCSF, followed by a clinical fellowship in body MRI and nuclear medicine at Stanford Medical Center in 2013. Dr. Hope's main research focus is on novel imaging agents. He is the principal investigator on the Ga-68 DOTA-TOC IND at UCSF and the Ga-68 PSMA-11 IND at UCSF. He has combined his interest in MR imaging with PET in the simultaneous modality PET/MRI, helping lead the development of the clinical PET/MRI program. Additionally, he is developing the PRRT (peptide receptor radionuclide therapy) program for neuroendocrine tumors at UCSF.

## **Alexandra Hotca-Cho, MD**

### **Assistant Professor Radiation Oncology, UCSF**

Dr. Hotca-Cho is a radiation oncologist specializing in cancers of the esophagus, liver, pancreas, bile ducts, and gastrointestinal tract. She also has expertise in treating metastatic cancers, particularly those that have spread to the lungs and bones. At the UCSF Helen Diller Family Comprehensive Cancer Center, Dr. Hotca-Cho is actively involved in managing complex gastrointestinal malignancies, including neuroendocrine tumors. Dr. Hotca-Cho earned her medical degree from Drexel University College of Medicine and completed her residency in radiation oncology at the Icahn School of Medicine at Mount Sinai. Her clinical research is dedicated to enhancing patient outcomes by developing preventive strategies and identifying predictive biomarkers for radiation-induced toxicities, with the goal of improving overall quality of life for patients with cancer.

## **Myron Kwong, MD**

### **Senior Physician, Department of Oncology/Hematology, Kaiser San Jose Medical Center**

Dr. Kwong is a native San Franciscan and has been on staff at Kaiser San Jose since 2005. He specializes in Gastrointestinal and Pancreatic Oncology. He is Co-Director of the Kaiser Northern CA GI Neuroendocrine Tumor Program since 2014. In addition to full-time clinical patient care, he has been involved in electronic medical record implementation and clinical trials. In conjunction with other multi-disciplinary specialty NET team members, he particularly enjoys providing NET advice and consultation for our Kaiser physicians and patients.

## **Angela Laffan, MSN, NP**

### **Clinical Lead, UCSF Survivorship and Wellness Institute**

Angela Laffan is an Oncology-certified nurse practitioner with more than 30 years of experience in the field of oncology. Angela is originally from Australia where she completed her Bachelor of Science in nursing. Angela came to the US in 1998 and completed a Master of Science in Nursing with a minor in Integrative medicine at UCSF in 2003. Angela has always had a strong interest in holistic oncology care and 2016 co-created the UCSF Gastrointestinal Cancer Survivorship Program. Angela was also instrumental in the development of the Neuroendocrine Wellness Clinic which is a multidisciplinary clinic for patients living with NET's as a chronic illness. Currently, Angela is working on program development and survivorship research in her role at the UCSF Survivorship and Wellness Institute.

## **Paul Lindenfeld, MD**

### **Associate Professor of Medicine in the Division of Palliative Medicine, UCSF**

Dr. Lindenfeld is an attending physician in the Symptom Management Service at the Helen Diller Cancer Center at the Mission Bay campus and also the Outpatient Palliative Care Service at the Parnassus campus. Dr. Lindenfeld previously worked for 13 years in the field of primary care before completing a fellowship in hospice and palliative medicine at Cedars-Sinai Medical Center. He now works entirely in outpatient palliative medicine at UCSF where he provides symptom management, assists with advance care planning and supports patients with a variety of serious, chronic medical illnesses. Dr. Lindenfeld routinely provides palliative care to patients with malignancy, amyotrophic lateral sclerosis and other neurodegenerative illnesses, pulmonary fibrosis, advanced congestive heart failure and advanced kidney or liver disease. He is actively involved in teaching fellows, medicine and pharmacy residents, and medical students who are interested in learning about palliative medicine.

Dr. Lindenfeld's academic interests center upon improving the current state of symptom management in palliative medicine. Examples of his interests include: use of buprenorphine for pain management in palliative care, improved treatment of cancer pain, novel approaches to the treatment of painful chemotherapy-induced peripheral neuropathy and neuropathic pain, the repurposing of existing medications for more effective symptom management in palliative care, and the development of novel therapeutic agents for symptom management.

## **Sheila Lindsay, NP, MSN**

### **Nurse Practitioner, UCSF**

Sheila Lindsay is a nurse practitioner who manages the side effects of gastrointestinal cancer and its treatments, and runs our small NET clinic. Sheila Lindsay is a nurse practitioner who helps patients manage the side effects of gastrointestinal cancer and its treatments. She also teaches them about how to optimize their health and quality of life while undergoing therapy and during recovery. She earned her bachelor's degree in nursing from Creighton University, and her master's degree from UCSF's adult nurse practitioner program. Lindsay is a member of the Oncology Nursing Society and American Society of Clinical Oncology. In 2018, she was a guest speaker at the North American Neuroendocrine Tumor Society's annual conference.

## **Connie Li, NP**

### **Nurse Practitioner, GI Oncology, UCSF**

Connie Li is a nurse practitioner who helps patients manage the side effects of gastrointestinal cancer and its treatments, including rare neuroendocrine malignancies. She also supports patients through her survivorship clinic after definitive treatment of gastrointestinal cancers. She educates patients on improving and maintaining their quality of life during therapy and recovery. Connie earned her bachelor's degree in nursing from The Ohio State University. She earned her master's from The Ohio State University's family nurse practitioner program. She is medically fluent in Mandarin Chinese.

## **Juliette Linzer, MPH**

Juliette Linzer has been a caregiver to her husband, a NET patient, for 17 years. Having a 10-month old baby at the time of his father's diagnosis, Juliette has navigated the day-to-day realities, unexpected emergencies, and sensitive conversations with a child at all ages and stages of development. Juliette reaches out to spouses of newly diagnosed cancer patients, to offer support related to caregiving and parenting when a family member has cancer. She has worked in the field of public health policy, management, and evaluation for forty years. She holds a bachelor's degree in Science, Technology, and Society from Cornell University and a master's degree in health policy and management from the Harvard School of Public Health. Juliette has also completed certificate programs in facilitation, mediation, advanced cooperative planning processes, and non-profit leadership.

## **Michael Lister, RN, BSN, OCN Nurse, UCSF**

Michael Lister is a practice nurse in the gastrointestinal medical oncology department at UCSF. His work focuses on supporting patients as they manage symptoms from cancer and treatment. He earned his nursing degree from Duke University. He has presented at NANETs and ICGMV conferences on integrative medicine group visits and advance care planning. Michael is a member of the Oncology Nursing Society and North American Neuroendocrine Tumor Society.

## **Greta Macaire, MA, RD, CSO**

### **Oncologist Dietitian Nutritionist, UCSF Helen Diller Family Comprehensive Cancer Center**

Greta Macaire has specialized in oncology nutrition for close to twenty years. She offers patients nutrition guidelines for specific cancers, nutrition during treatment, and support on optimizing eating patterns to maximize wellness and quality of life. Greta is the nutritionist for the UCSF multidisciplinary neuroendocrine wellness clinic working with the team to address the unique holistic needs of patients living with metastatic neuroendocrine tumors.

## **Josh Mailman, MBA**

### **Patient Advocate, and President, NorCal CarciNET Community**

Josh Mailman was diagnosed with PNET in 2007. Josh is an internationally recognized advocate for NET patients and for clinical trials and nuclear medicine. He is the inaugural chair of the Society of Nuclear Medicine and Molecular Imaging's (SNMMI) Patient Advocacy Advisory Board, a member of The Education and Research Foundation for Nuclear Medicine and Molecular Imaging (ERF) Board, acting COO the World Association of Radiopharmaceutical and Molecular Therapy (WARMTH), and president of NorCal CarciNET Community. He is the sole patient representative to the Nuclear Regulatory Commission's Advisory Committee on the Medical Use of Isotopes. In addition, he is co-chair of the National Cancer Institute's Patient Advocate Steering Committee. Josh is also a member of the Board of Directors of the Neuroendocrine Tumor Research Foundation.

## **Rebecca Mirro, RN, BSN, OCN Nurse Navigator, UCSF**

Rebecca Mirro is a Nurse Navigator who assists patients and their families with PRRT-related education and symptom discussion, as well as ongoing coordination of PRRT treatments, provider appointments, lab completion, scan completion, and other aspects of your multidisciplinary care. She received her BSN at Ramapo College of New Jersey, and is an ONCC Oncology Certified Nurse. Rebecca has more than 8 years of Oncology Nurse Navigation experience. She presented an Abstract Poster as a part of NANETS 2020 "The Importance of Dedicated Nurse Navigation for PRRT Therapy" and was a speaker during NorCal CarciNET 2021 "Nurse Navigation for PRRT".

## **Claire K. Mulvey, MD**

### **Thoracic Medical Oncologist and Assistant Professor, UCSF**

While she treats a wide variety of lung cancers, Dr. Mulvey specializes in lung neuroendocrine cancers, including typical and atypical carcinoid tumors, large cell neuroendocrine carcinoma and small cell lung cancer. Mulvey's research centers on developing new treatments for lung neuroendocrine tumors as well as on improving outcomes and quality of life for patients with these cancers. She earned her medical degree at the University of Pennsylvania. She completed a residency in Internal Medicine and a fellowship in Medical Oncology at UCSF.

## **Eric Nakakura, MD, PhD Professor of Surgery, UCSF**

Dr. Nakakura is a cancer surgeon who specializes in tumors of the liver, pancreas, bile ducts, and gastrointestinal tract. He also treats soft tissue sarcomas, including retroperitoneum, trunk, and extremities tumors. At UCSF Helen Diller Family Comprehensive Cancer Center, he participates in the management of complex gastrointestinal tract cancers, soft tissue sarcomas, and gastrointestinal neuroendocrine tumors, including carcinoid and islet cell tumors.

He earned a medical degree at Stanford University Medical School and a doctorate in cellular and molecular medicine at Johns Hopkins University. He completed a residency in general surgery at Johns Hopkins Medical Institutions and was a specialist registrar in surgery at the John Radcliffe Hospital in Oxford, England. He completed a fellowship in surgical oncology at Johns Hopkins. Dr. Nakakura, a Professor of Surgery at UCSF, conducts translational research on neuroendocrine tumors and soft tissue sarcomas.

## **Hong Song, MD, PhD**

### **Assistant Professor, Nuclear Medicine and Radiology, Stanford Medicine**

Dr. Hong Song is an Assistant Professor in the Division of Nuclear Medicine and Molecular Imaging at Department of Radiology of Stanford University. Dr. Song received his medical degree and PhD both from Tulane University. He completed an internal medicine internship at Tulane and his resident training in Diagnostic Radiology and Nuclear Medicine at Stanford University. Dr. Song is a physician scientist interested in developing and translating targeted radionuclide therapy particularly targeted alpha therapy for cancer treatment including neuroendocrine tumor (NET) and prostate cancer.

## **Jessica S. Thomas, LCSW**

### **Director of Patient Education, NETRF**

Jessica Thomas brings nearly two decades of experience as a clinical social worker helping patients and caregivers in neurology, oncology, and chronic illness. Most of her professional experience is as a mental health provider in the chronic illness field. Jessica's professional passion has been to empower patients and their caregivers to explore, find, and embrace their definition of "what matters most" while living with a chronic, progressive, or terminal illness. To help others find emotional wellness during physical illness. She cares greatly about community, patient-centered care, research, patient experience, and outcomes. Jessica has a BSW from Appalachian State University and an MSW from UNC-Chapel Hill.

## **Alexander Vezeridis, MD, PhD**

### **Assistant Professor of Radiology, Stanford Medicine**

Dr. Vezeridis is a physician-scientist specializing in Interventional Radiology. His clinical expertise includes interventional oncology, biliary disease and endoscopy, venous disease, portal hypertension, urologic interventions, women's and men's health interventions, and general vascular/interventional radiology. Dr. Vezeridis is an active researcher with expertise in translational techniques in engineering to make image-guided interventions safer and more effective for patients. He obtained his undergraduate, MD, and PhD degrees from Boston University. He completed post-doctoral training at UC San Diego in ultrasound molecular imaging under the auspices of the Cancer Researchers in Nanotechnology (CRIN) R25T, followed by residency and fellowship at UC San Diego.

## **Brendan Visser, MD**

### **Professor of Surgery, Stanford Medicine**

Dr. Visser completed his general surgery training at UCSF and then went on to complete his fellowship in Hepatobiliary and Pancreatic Surgery in Edinburgh, Scotland. He is the Chief of Hepatopancreatobiliary (HPB) Surgery and the Medical Director of the Gastrointestinal Cancer Care Program at the Stanford Cancer Center. He is a recognized expert in minimally invasive robotic liver and pancreatic surgery, and also performs the most complex operations involving vascular (blood vessel) reconstructions, ALPPS two-stage liver operations, and ex-vivo surgery (removing the organ from the body temporarily to allow removal of the tumor). He is the principal investigator on a trial of using peri-operative PRRT (peptide receptor radionuclide therapy) for advanced gastrointestinal neuroendocrine tumors.

## **Lisa Yen, NP**

### **Director of Programs & Outreach, LACNETS**

Lisa Yen was a nurse practitioner hospitalist for over 12 years prior to her husband's diagnosis with pancreatic NET in 2015. She brings a unique perspective to LACNETS as a medical professional and a caregiver.

Once a regional support group, LACNETS has grown into a national NET patient advocacy group that now supports the Carcinoid Cancer Foundation. Lisa curates educational content for LACNETS' educational programs, podcasts, video resource library and Clinical Trials Guide. She facilitates support groups and a support line. She has developed a peer mentorship program (NETCONNECT), a health coaching program and wellness retreats. Lisa also co-created NET VITALS with LACNETS founder, Giovanna Imbesi and City of Hope's Dr. Daneng Li. She was the recipient of the 2020 Monica Warner Award. She serves as treasurer on the executive board of INCA. She is a member of the NANETS NETPact Committee.

Lisa earned a BA in psychology from Wheaton College in Illinois, a BSN from Loyola University of Chicago, and a MSN from UCLA. Through Vanderbilt, she became a Nationally Board-Certified Health and Wellness Coach (NBC-HWC) and is currently on the Vanderbilt and VA faculty. She enjoys spending time with her husband, Tom, and their rescue dog, Skyler. She also enjoys traveling, snowboarding, and live theater.

# GLOSSARY OF TERMS

## A

**Atrophic Gastritis**—Inflammation of the lining of the stomach caused by infection from the bacteria known as *Helicobacter pylori*, and a risk factor for stomach cancer.

## C

**Carcinoid Crisis**—Carcinoid crisis causes a severe episode of flushing, low blood pressure, confusion and breathing difficulty. Carcinoid crisis can occur in people with carcinoid tumors when they are exposed to certain triggers, including anesthesia used during surgery. Carcinoid crisis can be fatal. Your doctor may give you medications before surgery to reduce the risk of carcinoid crisis.

**Carcinoid Syndrome**—Carcinoid syndrome is a group of symptoms associated with carcinoid tumors.

**Carcinoid Tumors**—Well to moderately differentiated neuroendocrine tumors in the stomach, intestine, appendix, rectum, and lung.

**Chemotherapy**—Anti-cancer drugs that are given either by mouth or by injection into a vein or muscle to kill cancer cells. Unfortunately, carcinoid tumors often do not respond well to chemo. Because of this, chemo generally is used only for tumors that have spread to other organs, are causing severe symptoms, and have not responded to other medicines.

**Chromogranin A (CgA)**—A sensitive biomarker in the blood of patients used to detect neuroendocrine tumors.

**Computed Tomography (CT) Scan**—A CT scan is an imaging method that uses x-rays to create pictures of cross-sections of the body.

**Crohn's Disease**—Crohn's disease causes inflammation of the digestive system. It is one of a group of diseases called inflammatory bowel disease. Crohn's can affect any area from the mouth to the anus. It often affects the lower part of the small intestine called the ileum.

## E

**Endocrine System**—Consists of cells that produce hormones. Hormones are chemical substances that are carried through the bloodstream to have specific regulatory effect on the activity of other organs or cells in the body. Part of the endocrine system is the neuroendocrine system, which is made up of cells that are a cross between traditional hormone-producing cells and nerve cells.

## G

**Gastrointestinal and Pancreatic Neuroendocrine Tumors (GEP-NETs)**—Tumors that originate in neuroendocrine cells of the embryological gut. Most commonly, the primary lesion is located in the gastric mucosa, the small and large intestine, the rectum and pancreas.

**Gastrointestinal Tract**—Also known as the GI tract or digestive system, it is the organ system that is responsible for consuming and digesting foods, absorbing nutrients from food and expelling waste. It includes the mouth, throat, esophagus, stomach, small and large intestines, rectum and anus.

## H

**Hormone**—Chemical substances that are carried through the bloodstream to have specific regulatory effect on the activity of other organs or cells in the body.

## I

**Insulin**—A hormone made by the pancreas that helps maintain normal blood sugar levels.

**Irritable Bowel Syndrome (IBS)**—A group of symptoms—including pain or discomfort in your abdomen and changes in your bowel movement patterns—that occur together.

## M

**Magnetic Resonance Imaging (MRI) Scan**—An MRI uses a large magnet and radio waves to look at organs and structures inside your body.

## N

**Neuroendocrine Cells**—Cells found mainly in the gastrointestinal tract but also scattered throughout the chest and abdomen, which release hormones into the blood in response to a signal from the nervous system. Neuroendocrine cells help control the release of digestive juices and how fast food moves in the GI tract. They may also help control the growth of other types of digestive system cells.

**Neuroendocrine System**—Part of the endocrine system and comprised of cells that are a cross between traditional hormone-producing cells and nerve cells.

## P

**Pancreas**—A pear-shaped gland located in the abdomen between the stomach and the spine. It is about six inches long and releases enzymes that help the body digest food. The pancreas also produces insulin, which helps control the amount of sugar in the blood.

**Pancreatic Neuroendocrine Tumor**—Pancreatic neuroendocrine tumors that form in hormone-making cells (islet cells) of the pancreas.

**Peptide Receptor Radionuclide Therapy (PRRT)**—A form of molecular targeted therapy which is performed by using a small peptide that is coupled with a radionuclide emitting beta radiation. PRRT is a novel nuclear medicine therapy for the systemic treatment of metastasized neuroendocrine tumors.

**Primary Tumor**—The original, or first, tumor in the body. Cancer cells can spread from a primary tumor to other parts of the body and form secondary tumors. This process is called metastasis.

## R

**Radiation**—The use of high-energy X-rays to kill cancer cells.

**Resection**—The surgical removal of an organ or structure, such as a tumor.

## S

**Secondary Tumor (metastasis)**—A tumor that forms from cancer cells that spread from a primary tumor to other parts of the body. The secondary tumor is the same type of cancer as the primary tumor.

**Somatostatin**—A hormone known for its ability to slow the release of other hormones and slow cell growth in the body.

## T

**Thyroid**—A gland that is part of the endocrine system and regulates hormones in the body. The thyroid absorbs iodine from the bloodstream to produce thyroid hormones, which in turn regulate metabolism.

## Z

**Zollinger-Ellison Syndrome**—A syndrome marked by severe recurrent stomach ulcers, esophageal reflux and diarrhea. It results from the overproduction of stomach acid caused by rare neuroendocrine tumors.

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