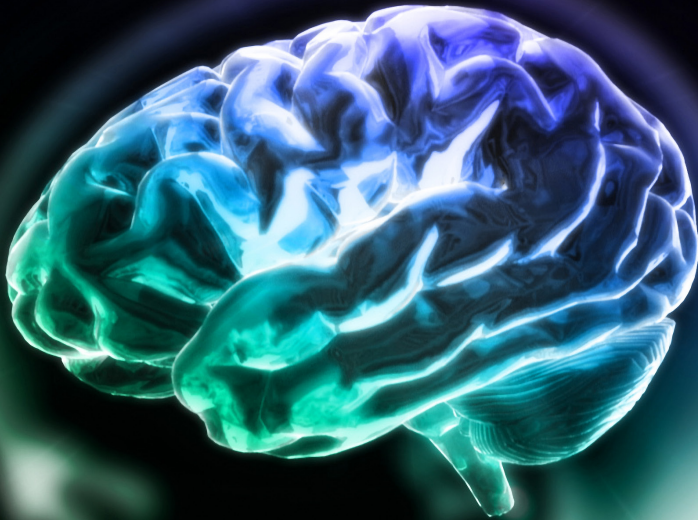


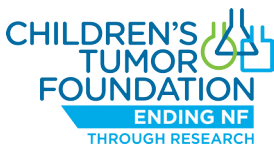
UCLA Health

Brain Tumor Center

2nd Annual UCLA NF2 & Schwannomatosis Symposium



This event is sponsored in part by



May 18, 2019

UCLA Carnesale Commons

251 Charles E. Young Drive West, 3rd Floor
Los Angeles, California

2nd Annual UCLA NF2 & Schwannomatosis Symposium

Hosted by the UCLA Brain Tumor Center & UCLA NF2 Multidisciplinary Clinic

JOIN patients, caregivers, and healthcare professionals at the 2019 UCLA NF2 & Schwannomatosis Symposium at the 19th Annual UCLA Brain Tumor Conference. Hear leading healthcare professionals speak about the latest treatments for brain tumors, symptom management and resources to help one manage and navigate living with the disease. Also meet with representatives from brain tumor organizations, health advocacy groups, and support groups to learn about resources available to the community.

TARGET AUDIENCE:

This educational event is targeted towards patients, caregivers, and family members. Healthcare professionals are welcome to attend, but please note, Continuing Medical Education units are not offered.

DATE & TIME:

Saturday, May 18, 2019 from 8:00 am to 1:30 pm

LOCATION:

UCLA Carnesale Commons
251 Charles E. Young Drive West
Los Angeles, CA 90095

REGISTRATION: FREE

SYMPOSIUM DIRECTORS

PHIOANH LEIA NGHIEMPHU, MD

Associate Professor of Clinical Neurology
UCLA Department of Neurology
UCLA Neuro-Oncology Program
Operations Director, UCLA Brain Tumor Center
Director, UCLA NF2 Multidisciplinary Clinic

MARCO GIOVANNINI, MD, PhD

Professor-In-Residence
UCLA Division of Head and Neck Surgery
Director, Neural Tumor Research Laboratory
Scientific Director, UCLA NF2 Multidisciplinary Clinic

SYMPOSIUM SPEAKERS

MARVIN BELZER, PhD

Adjunct Associate Professor, UCLA
Psychiatry & Biobehavioral Sciences;
Associate Director, UCLA MARC

JACQUELINE DILLON, LCSW

Clinical Social Worker,
UCLA Oncology Center

RICHARD EVERSON, MD

Assistant Professor, UCLA Neurosurgery

NANETTE FONG, RN, MSN, NP

Nurse Practitioner,
UCLA Neuro-Oncology

STACEY D. GREEN, DNP, RN

Doctor of Nursing Practice, Clinical
Research, UCLA Neuro-Oncology

AKIRA ISHIYAMA, MD

Chief, Olive View UCLA Head and
Neck Service; Director, UCLA Cochlear
Implant Program; Professor, UCLA Div
of Head and Neck Surgery

CAROLYN KATZIN, MS, CNS, MNT

Integrative Oncology Specialist,
Simms/Mann-UCLA Center for
Integrative Oncology

SHANNON LA CAVA, PsyD

Clinical Psychologist; Chief Clinical
Officer & Director of Programs and
Research, Cancer Support Community
Los Angeles

ALBERT LAI, MD, PhD

Professor, UCLA Neurology
UCLA Neuro-Oncology

JOAN MCCULLOCH, MS

Senior Speech Pathologist,
UCLA Audiology & Speech Pathology

LAUREN MICHELSON, RN, MSN, NP

Nurse Practitioner,
UCLA Neuro-Oncology

LAURIE MILLER, MSW

Clinical Social Worker,
Children's Hospital Los Angeles

DONNA MOLAIE, MD

Clinical Instructor, UCLA Neurology
UCLA Neuro-Oncology
DAYANA PELAYO, ESQ
Staff Attorney,
Cancer Legal Resource Center

MICHAEL SIEVERTS

Qi Gong Instructor

RACHAEL ANNE SINGER, MS, R-DMT

Registered Dance/Movement Therapist

KATHLEEN VAN DYK, PhD

Clinical Instructor & Neuropsychologist,
UCLA Geriatric Psychiatry

NEIL WENGER, MD, MPH

Professor, UCLA Medicine & Health
Services Research
Director, UCLA Health Ethics Center

JACQUELINE ZARAGOZA

Public Affairs Specialist,
Social Security Administration

SATURDAY, MAY 18, 2019

8:00-9:00am Registration, Continental Breakfast & Resource Fair Exhibits

NF2 & Schwannomatosis Track

9:00-9:05am **Introduction to NF2/SWN Symposium**
Leia Nghiemphu, MD

9:05-9:45am **Introduction to NF2/SWN Tumors**
Marco Giovannini, MD, PhD

Attend this session to get an overview on NF2, incidence, introduction to treatment options, and scientific discoveries related to NF2 and Schwannomatosis

9:45-10:15am **Surgical Treatment Options for NF2/SWN**
Richard Everson, MD

Dr. Everson will discuss when is surgery indicated for the treatment of NF-related tumors.

10:15-10:45am **Patient Experience with NF2/SWN**
Onno Faber

Mr. Faber will discuss how to collect medical records and data and maintain control of health records as a NF2/SWN patient.

11:00-11:30am **Auditory Rehabilitation in NF2/SWN**
Akira Ishiyama, MD

11:30-12:00pm **Updates in Clinical Trials for NF2/SWN**
Leia Nghiemphu, MD

Breakout Sessions

9:00-9:45am **A. Symptom Management**

Lauren Michelson, RN, MSN, NP

Symptoms from brain tumors and side-effects from associated treatments are discussed. Learn about what you can do to manage them.

B. Legal Issues: Employment & Benefits

Dayana Pelayo, Esq.

Navigating a cancer diagnosis in the workplace poses potential challenges and pitfalls. This presentation will discuss laws that offer protections to patients in various stages of employment and discuss ways that employees can use those laws to maintain income and access benefits.

C. Qi Gong Exercise

Michael Sieverts

Qi gong means "the study of energy." Participate in this exercise, which is a series of movements and coordinated breathing that is designed to maintain shining health and excellent focus. Learn how to integrate this exercise into recovery.

D. Understanding the Caregiver Experience: A Caregiver Panel (*Caregivers Only)

Jacqueline Dillon, LCSW

Caregivers are often faced with challenges when their loved one is diagnosed with a brain tumor. Attend this session to hear from a panel of caregivers share their experiences and how they manage to cope with the effects it has had on their lives.

10:00-10:45am **A. Overcoming Cognitive Challenges after Brain Tumor Diagnosis and Treatment**

Kathleen Van Dyk, PsyD

Dr. Van Dyk, a UCLA neuropsychologist specializing in cancer survivorship, will discuss common cognitive difficulties that may develop after a brain tumor. She will review how these cognitive challenges can impact a person's daily life, and go over supportive cognitive strategies to improve day-to-day functioning. Dr. Van Dyk will also describe cognitive rehabilitation services at UCLA.

B. Integrating Psychosocial Support Into Treatment: A Patient- Survivor Panel

Shannon La Cava, PsyD

Please join in this open discussion and Q&A with participants from the Brain Tumor Support Group at Cancer Support Community Los Angeles. Topics will include making treatment decisions, side effects of care, and the social and emotional impact on a person diagnosed with a brain tumor. Bring your questions and join the inspiring and educational workshop.

C. Seizure Management

Donna Molaie, MD

A seizure is a common symptom that brain tumor patients may experience. In this session, learn about classification, causes, and risk factors of seizures. Also learn how seizures can be managed and what medications are used for treatment.

D. Navigating Health Insurance

Dayana Pelayo, Esq.

Health insurance can be complex and frustrating to patients attempting to advocate for care. This presentation will offer ideas and strategies to allow patients to learn what health insurance options exist and how to get the most out of their existing plan.

11:00-11:45am **A. Understanding Clinical Trials**

Stacey Green, DNP, RN

Clinical trials are research studies aimed at improving health and treatments. Find out more details about different types of clinical trials, why they are conducted, who is eligible to participate, and the pros and cons of participating in a trial.

B. Coping with Aphasia

Joan McCulloch, MS

Aphasia is a speech-language comprehension disorder that can be caused by brain tumors. Learn about aphasia and what therapies are available.

C. Advance Care Planning

Neil Wenger, MD, MPH

It is important to discuss with your loved ones your wishes and plans for your future healthcare and end of life care. This session will cover things you should consider to ensure your preferences for your future care are met in the event you are unable to communicate or make your decisions on your own.

D. The Basics of Mindfulness for Self Care and Stress Management

Marvin G. Belzer, PhD

Mindfulness is the art of openly and actively paying attention to experience in the present moment. This approach has scientific support as a means to reduce stress, improve attention, boost the immune system, reduce emotional reactivity, and promote a general sense of health and wellness. This workshop will engage participants in several experiential practices where they will explore the basics of mindfulness meditation as well as methods to cultivate positive emotions, with special emphasis on the reduction of stress.

12:00-12:45pm Lunch & Resource Fair Exhibits

12:45-1:30 pm A. Understanding the Family Experience

Jacqueline Dillon, LCSW

Listen to a panel of patients and family members share experiences with brain tumors and how they have managed to cope with the effects it has had on their lives.

B. Nutrition for Brain Tumor Patients

Carolyn Katzin, MS, CNS, MNT

Learn about brain metabolism and nutrition, what foods provide benefit for brain tumor patients, barriers to eating healthy, and managing diet during treatment and while living with a brain tumor.

C. End of Life Issues: Symptoms and Clinical Transitions

Nanette Fong, RN, MSN, NP

Learn about what occurs in the end stage of brain cancer, what changes to expect, and care options that are available such as palliative care and hospice care.

D. Movement for Mind, Body, and Spirit

Rachael Anne Singer, MS, R-DMT

Experience the stress-reducing and mood-lifting power of movement with music, as you listen to your body and allow it to guide you without judgment. Discover the joy and connection with others that this may bring. It may even reduce your pain. These are activities that you can do on a daily basis for self-care.

E. What You and Your Family Should Know About the Social Security Disability (SSDI) Program and the Supplemental Security Income (SSI) Disability Program

Jacqueline Zaragoza

The Social Security Administration administers disability benefits for many people. Social Security reaches almost every family, and at some point will touch the lives of nearly all Americans. In this session, learn about the SSDI and SSI Programs and how it can help workers who have become disabled.

F. Support for Families of Children with Brain Tumors

Laurie Miller, MSW

Facing the challenges of having a child diagnosed with a brain tumor can be overwhelming for the family. Attend this session to learn about helping the family understand the disease, ways families can cope, and guidance on seeking support.

ABOUT UCLA NF2 MULTIDISCIPLINARY CLINIC

The UCLA Multidisciplinary NF Clinic offers a comprehensive multidisciplinary approach for neurofibromatosis type 2 (NF2) and schwannomatosis patients. The core team includes pediatric and adult neuro-oncologists, neurosurgeons, neuro-otologists, and clinical geneticists. The team convenes regularly with a panel of experts in relevant sub-specialties (neuro-ophthalmology, neuro-radiology, neuro-pathology, audiology) and with NF2 specialists at the House Clinic, to design an individualized patient and family-centered plan of care to meet each patient's unique medical needs. The UCLA NF2 Clinic is one of the few in the country that sees both adults and children. As part of UCLA Health, the NF2 clinic provides access to state-of-the-art imaging and surgical facilities as well as world-renowned experts in "bench to bedside" NF research and clinical trials.

The UCLA NF Clinic is part of a national and international collaboration of medical centers and providers seeking to find the best treatments for patients with NF and to advance research. Their goal is to provide a patient-centered medical home for this life-long, complicated syndrome. Care providers at the UCLA NF Clinic are part of one of the largest brain and peripheral nerve tumor centers in the world. The clinic is designated as an affiliated clinic of the Children's Tumor Foundation and is part of the Department of Defense-sponsored NF Clinical Trials Consortium. Our clinic director is also a member of the Response Evaluation in Neurofibromatosis & Schwannomatosis (REINS) International Collaboration.

To learn more about the UCLA NF Clinic, please visit www.neurosurgery.ucla.edu/neurofibroma

2ND ANNUAL

UCLA NF2 & SCHWANNOMATOSIS SYMPOSIUM

AT THE UCLA BRAIN TUMOR CONFERENCE

Registration by fax must be submitted by
Tuesday, May 14, 2019 to: (310) 825-0644

Registration by mail must be postmarked
by Saturday, May 11, 2019 and mailed to:
UCLA NF2 Symposium
c/o UCLA Neuro-Oncology Program
710 Westwood Plaza, RNRC Suite #1-230
Los Angeles, CA 90095

Online registration must be submitted by
Tuesday, May 14, 2019 at the following website:
www.uclahealth.org/braintumor

**QUESTIONS? Please call (310) 206-3610 or
email neuroonc@mednet.ucla.edu**

If registering family members/companions, please complete a separate registration form for each.

FIRST & LAST NAME _____

I AM A: patient caregiver family member other _____

PREFERRED MAILING ADDRESS: _____

CITY/STATE/ZIP: _____

TELEPHONE: () _____ FAX: () _____

E-MAIL ADDRESS: _____

PLEASE CHOOSE SESSIONS YOU WISH TO ATTEND

You may choose any combination of NF2 Track Sessions and Breakout Sessions

NF2 & SCHWANNOMATOSIS TRACK

9:00-9:45^{am} Introduction to Symposium and NF2/SWN Tumors

9:45-10:15^{am} Surgical Treatment Options for NF2/SWN

10:15-10:45^{am} Patient Experience with NF2/SWN

11:00-11:30^{am} Auditory Rehabilitation in NF2/SWN

11:30-12:00^{pm} Updates in Clinical Trials for NF2/SWN

BREAKOUT SESSIONS

9:00-9:45^{am} A. Symptom Management B. Employment & Benefits
 C. Qi Gong D. Understanding the Caregiver Experience

10:00-10:45^{am} A. Cognitive Challenges B. Integrating Psycho-Social Support
 C. Seizure Management D. Navigating Health Insurance

11:00-11:45^{am} A. Clinical Trials B. Coping with Aphasia
 C. Advance Care Planning D. Basics of Mindfulness

12:45-1:30^{pm} A. Family Experience Panel B. Nutrition
 C. End of Life Issues D. Movement for Mind, Body, & Spirit
 E. SSI & SSDI Benefits F. Support Families of Children w/Brain Tumors

DO YOU REQUIRE A VEGETARIAN MEAL? yes no

DO YOU REQUIRE SPECIAL ASSISTANCE? yes no Please Specify: _____

CURRENTLY RECEIVING TREATMENT AT UCLA? yes no

HOW DID YOU HEAR ABOUT THIS CONFERENCE? _____

DIRECTIONS & PARKING INFORMATION

CONFERENCE LOCATION:

UCLA Carnesale Commons
251 Charles E. Young Drive West 3rd Floor
Los Angeles, CA 90095

PARKING LOCATION:

Parking Structure Sunset Village (PSV) with additional parking available in Structure 7

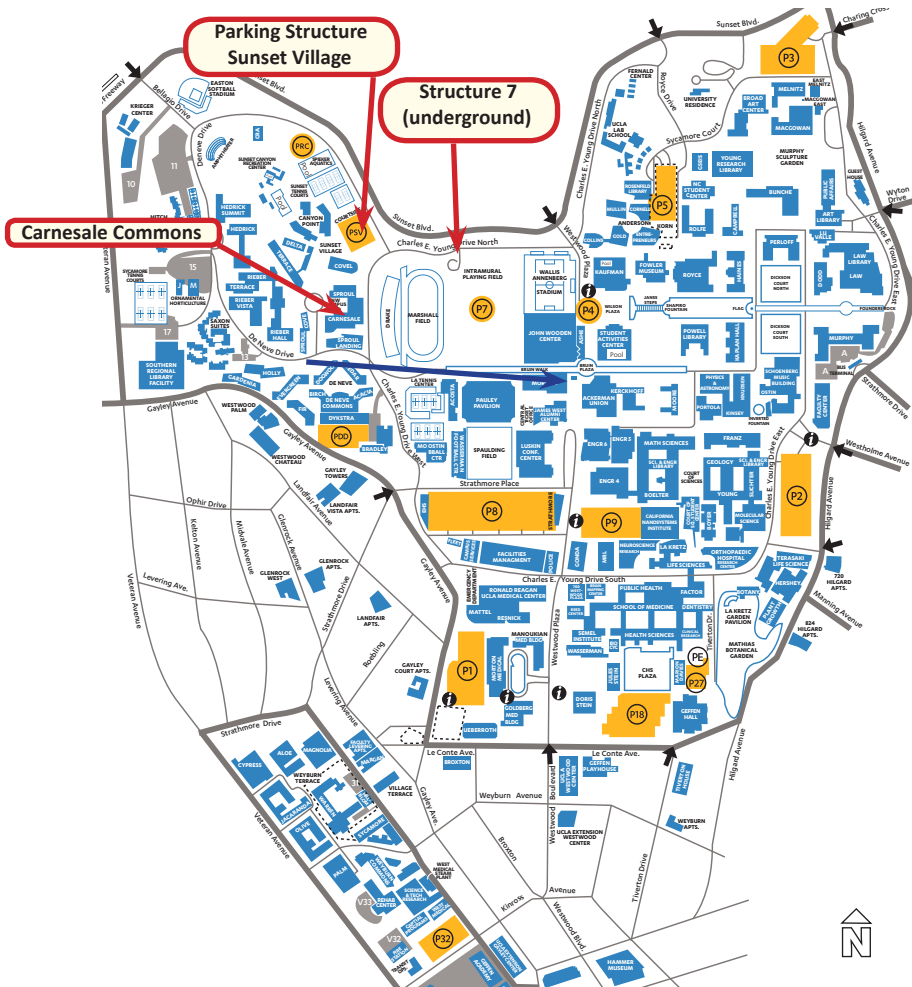
PARKING CHARGES:

Free with Coupon Code: CCBTC519
(see below for instructions on how to obtain a free parking pass)

Without Coupon Code:

\$12 for Daily Parking Permit

\$9 for Daily Disabled Parking Permit



DIRECTIONS

Take the San Diego Freeway (I-405). Exit Sunset Blvd EAST. Head EAST on Sunset Bl, past Veteran Ave. Turn RIGHT at Bellagio Drive. Make a LEFT at the stop, and continue down the road. Parking Structure Sunset Village (PSV) will be on your Right. [Prior to parking, you may choose to drop off guests at the front entrance of Carnesale Commons.]

To obtain your complimentary parking pass:

1. Enter Parking Structure SV or Structure 7 and park in any unreserved stall.
 2. Go to the nearest parking Pay-Station to obtain your self-parking daily permit.
 3. When prompted, enter your license plate number into the parking pay station by using the number pad.
 4. Select "Commuter Club" from list of rates. You may have to select More Options if "Commuter Club" does not appear on the first screen.
 5. When prompted, enter Coupon Code **CCBTC519**.
 6. Please retain permit as a receipt for parking.
- It is not necessary to display the permit on the vehicle, unless it is not displaying a license plate. If the vehicle does not have plates, there are instructions to enter the last six digits of the VIN and then display to permit on the driver's side dash.

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c/o UCLA Neuro-Oncology Program
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Los Angeles, CA 90095

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