









### WELCOME TO THE NEUROLOGY AND NEURO-ONCOLOGY TEAM AT PROVIDENCE SAINT JOHN'S MEDICAL CENTER

We are privileged to have been chosen as your care team. We recognize how difficult and challenging it can be to carry a new diagnosis of this nature. At our center, we aim to offer the latest clinical trials and treatment options, but we also work hard to ensure that each patient's care is customized and individualized. Our goal is to walk with you on this journey, providing the medical advice, resources, and support you and your loved ones need.

We are able to do this through a unique team model. Our team is made up of physicians, advanced practice providers, nurses, medical assistants, administrative assistants, research coordinators, and social workers. We also work closely with the neurosurgery, radiation oncology, and psycho-oncology teams. This means that you benefit from the expertise and care of many different professionals who have different strengths – together, we provide the comprehensive care you should receive.

This may also mean that you may not see the same individuals at each visit. We want you to get to know our whole team! Please find in this treatment organizer an introduction to all the members who make up your care team, and their roles in our team.

A relationship with the medical system can be very overwhelming. There is so much information to process — on your condition, treatment plans, research, and prognosis. There are risks and benefits to consider, pros and cons to weigh. There are so many appointments to keep track of, new medications and dosing changes, labs and testing. All of this can naturally lead to stress and anxiety on you and your loved ones. We created this treatment organizer to help alleviate this to some degree — our aim is to provide a single place for you to keep your medical details, important contact information, your treatment plan, and resources that we think you will find helpful. We suggest bringing this organizer with you to future appointments, so we help you keep it updated.

Thank you for trusting us with your care!





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Your Medical History	Keep a record of your diagnosis-related history & overall medical history	6
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Calendar	Keep track of appointments, medication start and end dates, etc.	17
Notes	Blank pages for you to write down key details from visits, phone numbers, questions for your next visit	19

	HANDOUTS	
Meet Your Care Team	Know who is taking care of you	
Detailed Contact List	Important phone numbers	

Other resources may be given to you at a later time, when the need or question arises





### **GENERAL OFFICE FAQS**

HOW TO	INSTRUCTIONS	
Change/Cancel appointments	<ul> <li>Please try to cancel your appointment at least 2 business days before your scheduled appointment</li> <li>Please send a message through MYCHART whenever possible (or call 310-829-8265)</li> <li>To obtain an appointment time/date of your preference, requests made 2 weeks in advance provide the most options</li> </ul>	http://mychartor.providence.org Call: 310-829-8265
Ask <b>SIMPLE</b> medical questions	<ul> <li>Please use MYCHART during business days/hours for fastest response to any simple/non-urgent medical questions</li> <li>You may also request refills using MYCHART</li> </ul>	http://mychartor.providence.org
Ask <b>URGENT</b> medical questions	<ul> <li>Please call 310-829-8265 and ASK FOR PHYSICIAN ON CALL TO BE PAGED</li> <li>On call MD is available 24/7, after work hours/weekends</li> </ul>	Call: 310-829-8265
Use Mychart	<ul> <li>There is also a MYCHART APP for Iphones/Android phones</li> <li>Through your portal you can:         <ul> <li>Ask non urgent medical questions</li> <li>Reschedule/cancel ask for a new appointment</li> <li>Request refills</li> <li>See your lab/imaging results and more</li> </ul> </li> </ul>	http://mychartor.providence.org
Request Letters, forms, disability, etc.	<ul> <li>Medical/work letters, DMV/FMLA forms will take 5-7 business days to complete</li> <li>There may be a \$15-\$25 charge per request that you will be responsible for</li> <li>For EDD state disability requests, please submit online and provide to us the Receipt "R#####"</li> </ul>	State Disability: <a href="https://edd.ca.gov/">https://edd.ca.gov/</a>
Obtain my scans?	<ul> <li>Preferred imaging center is Tower Saint John's Imaging</li> <li>We recommend you request copies of your imaging directly from Tower Imaging</li> </ul>	2202 Wilshire Blvd. Santa Monica, CA 90403 Phone: 310-264-9000
	<ul> <li>If you need help with walking, we also use Providence Saint John's Hospital imaging (please tell your team)</li> </ul>	2121 Santa Monica Blvd. Santa Monica, CA 90404 Phone: 310-829-8000
Mail CDs	Please Fedex/UPS/USPS Tracking to mail your CD	2200 Santa Monica Blvd. Santa Monica, CA 90404
Get to Clinic	<ul> <li>Clinic is located in Providence Saint John's Health Center on the GARDEN LEVEL (basement)</li> <li>Please see MAP handout for more details</li> </ul>	2121 Santa Monica Blvd. Santa Monica, CA 90404
	HOURS OF OPERATION OFFICE: Monday – Friday 8 a.m. – 4:30 p.m. INFUSION: Tuesday – Thursday 8 a.m. – 3 p.m. *Major holidays are observed, please check with of	





### **CALLING YOUR HEALTH CARE PROVIDER**

To expedite the process, the following information will be helpful -	
Name:	
Date of Birth:	
Provider's Name:	
Diagnosis:	
If you are having a fever or other symptoms, it may be helpful to record y reminding you of the details you wish to discuss.	your current temperature or write a note
ZONE TOOL	
ALL CLEAR ZONE No fever Pain Controlled Nausea controlled Oral intake is normal No other concerning symptoms	Use MyChart to request refills, ask questions, or report non-urgent symptoms

### WARNING ZONE

Fever of 100.4C or higher
Uncontrolled or new pain
Nausea or vomiting that can't be controlled
Severe diarrhea, constipation, urinary problems
New numbness or tingling
Brief, self-resolving, breakthrough seizures

Cough/Congestion
New Rash
Unexplained bleeding
New swelling
Worsening fatigue
Very high or low BP

Call the office at 310-829-8265; After hours/weekends ask for on-call doctor

### **MEDICAL ALERT ZONE**

Loss of consciousness
New/first seizure
Seizure > 3 minutes or > 2 seizures in 15 mins
Fall with head injury
Confusion and lethargy
Sudden onset weakness

Difficulty or inability to speak New facial droop

Go to the Emergency Room OR Call 911





### **IMPORTANT CONTACTS**

Name		Name	
Relationship		Relationship	
	Med Release Y  N		Med Release Y 🗌 N 🗌
Physician Information			
Primary Care Physicia	n	Neurosurgeon	
Name		Name	
Phone		Phone	
Address		Address	
Neuro-Oncologist/On	cologist	Radiation Oncologist	
Name		Name	
Phone		Phone	
Address		Address	
	Other Specia	llist Provider:	·····
	Name		_
	Phone		_
	Address		





### YOUR MEDICAL HISTORY

Diagnosis	Date o	Date of Diagnosis//		
Treatment History (provide information	SPECIFIC to	o your CU	RRENT DIAGNOSIS)	
Surgical History				
Type of Surgery & reason for surgery		Location	of Surgery (Hospital)	Date of Surgery
				<u> </u>
Radiation History				
Radiation location (on body)		Location	of Radiation (Hospital)	Start Date – End Date
			a dia ana aia	
<b>Chemotherapy</b> and/or Medication Hist (please include any devices, alternative the				
Medication	Dose (mg		Frequency (daily/weekly)	Start Date – End Date





Past Medical History (please check all that apply and indicate date of diagnosis)

Asthma:			Autoimmune Disor	der:
Anemia:			Brain Tumor:	
Blood Clots:			Blood Transfusion:	
Colon Polyps:			Diabetes:	
Emphysema:			Heart Disease:	
High Blood Pre	essure:		Jaundice/Cirrhosis:	
Kidney Disease	2:		Menopause:	
Prostate Disea	se:		Seizures:	
Stroke:			Thyroid Disease:	
Headaches:			Other:	
Other than those listed	d on Page 2, have you had	any other prio	r surgeries? Please list.	
				Date of Surgery
Other than those listed			r surgeries? Please list. of Surgery (Hospital)	Date of Surgery
				Date of Surgery
				Date of Surgery
				Date of Surgery
				Date of Surgery
				Date of Surgery



**MEDICATIONS** 



Preferred PharmacyPhone				
Address				
Please list all medications & supplement			(or attach a list)	
Medication Name	Dose	Frequency (daily/weekly/as needed/etc)	Start date – End Date	
SUPPLEMENTS  Are you taking anything over the counter, any no please list them here.	atural or alterna	tive treatments, vitamins or ar	nything else at all?	
Name	Dose	Frequency (daily/weekly/as needed/etc)	Start date – End Date	





### **IMAGING RECORD**

Type of Imaging + Date	Location	Main Takeaway





### **MY CURRENT TREATMENT PLAN**

Remember to date any updates

My current treatment plan is:
My current steroid dose is:
My seizure treatment plan is:
My symptom management plan is:





### **MY CURRENT TREATMENT PLAN**

Remember to date any updates

My current treatment plan is:	
iny carrent deathless plants.	
My current steroid dose is:	
Note a circums transfer and relative	
My seizure treatment plan is:	
My symptom management plan is:	





We provide these resources as a way for you to gain more information, get connected, and feel more empowered.

Always remember information online is imperfect and can be inaccurate. Talk to your medical provider before following any advice you find through these websites or communities. Please note that we have no relationships with any of these websites/resources; these are simply resources we have gathered over the years.

Our website provides information on our philosophy and goals, our team members, additional resources, and information on current/upcoming clinical trials.

Pacific Neuroscience Institute <a href="https://www.pacificneuroscienceinstitute.org/">https://www.pacificneuroscienceinstitute.org/</a>

The organizations below focus on brain tumor specific education, support, advocacy, fundraising, and research efforts. Each organization provides helpful resources and education on different tumor types, and you can find information on local events and support groups. Free online support groups as well as education series may also be available.

**End Brain Cancer** (<u>www.endbraincancer.org</u>)

National Brain Tumor Society (www.braintumor.org)

American Brain Tumor Association (www.abta.org)

The Brain Tumor Foundation (www.braintumorfoundation.org)

This is a nonprofit organization that can assist with services such as lodging, transportation, treatment, wigs, etc. Visit the website to find a local chapter or call (800) 227 2345.

**American Cancer Society (www.cancer.org)** 

Cancer Care offers free, professional counseling and support by phone. Other resources include online classes, publications, and financial aid programs. Email – <u>info@cancercare.org</u>; Phone – (800) 813 HOPE (4673).

Cancer Care (www.cancercare.org)

Support for caregivers.

Cancer Support Community for Caregivers (https://www.cancersupportcommunity.org/caregivers)

Family Caregiver Alliance (<u>www.caregiver.org</u>)

Privately and publicly funded clinical trials around the world can be researched at the Clinical Trials website.

Clinical Trials (www.clinicaltrials.gov)





This toolbox includes a free, self-learning audio program, available online or via CDs that can be ordered for home use. Call the National Coalition of Cancer Survivorship at (310) 650 9127 or <a href="mailto:info@canceradvocacy.org">info@canceradvocacy.org</a>.

The Cancer Survival Toolbox (www.canceradvocacy.org/toolbox)

Many blogs and social media accounts also provide support, friendship, education, and connect patients and caregivers to the larger brain tumor community.

Follow the hashtag #btsm or @BTSMchat on Twitter (BTSM – Brain Tumor Social Media).

### Readings:

Navigating Life with a Brain Tumor (a book written by neuro-oncologists Alyx Porter and Lynne Taylor with attorney Diane Richard)

The Median Isn't the Message (Stephen Jay Gould, available online at no cost)

Other lists of books that patients and their families have found helpful:

https://www.braintumourresearch.org/info-support/resources/recommended-brain-tumour-books

https://www.ucsfhealth.org/education/resources-for-brain-tumor-patients-with-children

https://bookauthority.org/books/best-brain-cancer-books

Planning for the future will include important and at times difficult conversations, along with key documentation and paperwork. Regardless of your diagnosis or prognosis, it is always a good idea to be prepared. These resources provide support and guidance for this process and we are also happy to discuss this further during your visits.

**Get Palliative Care** <a href="https://getpalliativecare.org/">https://getpalliativecare.org/</a>

The Conversation Project https://theconversationproject.org/

Five Wishes <a href="https://fivewishes.org/">https://fivewishes.org/</a>

**Prepare for your Care** https://prepareforyourcare.org/welcome

Advance Care Planning https://www.nhpco.org/patients-and-caregivers/advance-care-planning/advance-directives/

Shared Decision Making <a href="https://www.fairhealthconsumer.org/shared-decision-making">https://www.fairhealthconsumer.org/shared-decision-making</a>





### FINANCIAL ASSISTANCE, COUNSELING & INSURANCE

Our social workers are available to you for these questions – we can set up a visit for you as/when needed.

Please keep your insurance details handy – take a picture of the card on your smartphone for easy access.

Read the policy. Ask if your company offers a case manager. Call and ask questions for anything you don't understand – don't be shy and hesitate!

Keep all bills and letters in an organizer – don't throw anything out.

Always get the name and employee ID of the person you are speaking with. Take notes or have a friend help.

Additional resources include:

Information and resources on cancer-related legal issues including insurance coverage, access to healthcare, government benefits, etc. Call CLRC at (866) THE CLRC (843-2572) or email them at <a href="CLRC@DRLCENTER.ORG">CLRC@DRLCENTER.ORG</a>

**Cancer Legal Resource Center (www.cancerlegalresources.org)** 

Career coaching, support groups, educational seminars surrounding working with cancer.

Cancer and Careers (www.cancerandcareers.org/en)

State health insurance assistance program – free local health coverage counseling for people with Medicare.

https://finder.healthcare.gov/

Other resources for financial assistance/counseling:

Patient Advocate Foundation <a href="https://www.patientadvocate.org/">https://www.patientadvocate.org/</a> or (800) 532 5274

Partnership for Prescription Assistance www.pparx.org

NeedyMeds www.needymeds.org or (800) 503 6897

RxHope www.rxhope.com





### **TIPS**

Providing information and updates to loved ones and your community can get exhausting and overwhelming. We recommend appointing a spokesperson in your family/friend community who others can reach out to.

Another alternative is using a website that allows you to keep an updated blog.

Caring Bridge www.caringbridge.org Also available as an app on iPhone/iPad/Android.

In times like these, you need your community. It is OKAY to ask for help and we encourage it. Our experience is that often people want to help but don't know what to say or do. These apps make it easier for everyone involved and provide lots of help to you in staying organized.

**Lotsa Helping Hands** <a href="https://lotsahelpinghands.com/">https://lotsahelpinghands.com/</a> - Family, friends, volunteers can all join and manage errands, appointments, gatherings, meals. There is also a message board for updates. Available for free on iPhone/iPad.

**Caring Village** <a href="https://www.caringvillage.com/">https://www.caringvillage.com/</a> – Caregivers can coordinate and track their loved one's care – centralized calendar, medication list, wellness journals. Great for big families and multiple caregivers. Available for free on iPhone/iPad/Android.

CareZone <a href="https://carezone.com/home">https://carezone.com/home</a> — A secured app that allows family and friends to view important information, share a task list, get and send updates. You can take a picture of meds/prescriptions and the app adds them for you. It can send you reminders and help keep track of appointments. Available for free on iPhone/iPad/Android.

Symptom tracking can be overwhelming but important so you can share these details with us, especially if you are in a clinical trial. These apps make it easy and save you time.

### Chemowave

**Cancer Treatment Tracker** 

### CancerGraph

If you are taking any supplements or are interested in any naturopathic treatments for your condition, we welcome a discussion on this. We want communication around this to be open and honest so we keep this in mind when writing any prescriptions for you or drawing any labs. We may also have some suggestions to optimize the use of these treatments/supplements.

**ConsumerLab.com** and **Examine.com** are two websites that provide independent analysis on supplements (which are not regulated by the FDA).





SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
NOTES:						





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SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
NOTES:						





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### **PHYSICIANS**



Santosh Kesari, MD, PhD



Jose Carrillo, MD



Naveed Wagle, MD



Akanksha Sharma, MD

# **ADVANCED PRACTICE PROVIDERS**



Minh Nguyen, MHS, PA-C Judy Truong, PA-C



Jared Chow, PA-C, MIMS



Eve Landa, MPH, MSHS, PA-C





## **CLINICAL NURSES**



Theresa Martello, BSN, CCRN



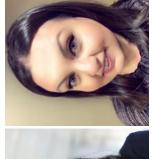
Susan Koh, RN, BSN

## **ADMINISTRATIVE SUPPORT**



Nancy Linares

Sabrina Boyce



Hermine Bagdoyan Selenia Claros



## **RESEARCH TEAM**



Jaya Mini Gill, RN,



Annie Heng, RN, BSN



BS



Hahn Nguyen-Thuy, DeLisa Madere, BS Raffi Nersesian, BS Ashley Archer, BS



Saint John's
Health Center





**CONTACT INFORMATION** 

Hours of Operation: Monday – Friday 8 a.m. – 4:00 pm (Closed Holidays & Weekends)

MyChart: <a href="http://mychartor.providence.org/mychart">http://mychartor.providence.org/mychart</a> (a secure and fast way to communicate with your team)

After your first visit, you will receive instructions on how to sign up for MyChart. This is the primary way you will communicate with your care team. Results, questions, medication refills, scheduling can all be done through this portal in a protected and secure way.

Recource	Namo	Dhone	Eav	MyChart
Medical	Dr. Santosh Kesari. MD. PhD	(310) 879-8765	(310) 582-7287	General Medical Questions: please use
Questions	Dr. Jose Carrillo, MD	0010 010 (010)	100 (010)	Mychart for fastest response
,	Dr. Naveed Wagle, MD			
	Dr. Akanksha Sharma, MD			<b>EMERGENCIES AFTER HOURS</b> : please
	Judy Truong, MPAP, PA-C Physician Assistant			call 310-829-8265 and ask for MD to be
	Minh Nguyen, MHS, PA-C Physician Assistant			paged (even for after hours)
	Evie Landa, MPH, PA-C Physician Assistant			
Scheduling	Nancy Linares Clinical Administrative Associate	(310) 829-8265	(310) 582-7287	MyChart preferred for fastest and
Insurance	Sabrina Boyce Clinical Administrative Associate			secure response
Letters/FMLA	Hermine Bagdoyan Clinical Administrative Associate			
Clinical Trials	Annie Heng, RN, BSN Clinical Research Nurse	(310) 582-7457	(310) 582-7287	MyChart preferred for fastest and
	Hanh Nguyen Clinical Research Associate	(310) 582-7434		secure response
	Ashley Archer Clinical Research Associate	(310) 582-7460		
	Raffi Nersesian Clinical Research Associate	(310) 829-8808		
	DeLisa Madere Clinical Research Assistant	(310) 499-5271		
Medical	Medical Records Department	(310) 829-8946	(310) 315-6148	Basic labs and imaging will be available
Records	Hours: 8 am to 4:30 pm Mon-Friday			on MyChart
<b>Imaging Center</b>	Tower St. John's Imaging	(310) 264-9000		Not applicable
	2202 Wilshire Blvd. Santa Monica, CA 90403			
Financial &	Financial and Billing Department	(310) 582-7254		Not applicable
<b>Billing Services</b>		(310) 582-7457		