NATIONAL SURVIVOR VOLUNTEER NETWORK

Please check all areas that apply to you

Name__________________________________date of birth___________ Phone (H)_________________(B)__________________

Address____ Best Time to Call________________________________

City____ Email____

State and Zip code_______________________________________ Fax____

Would you be willing to return a phone call? Within your state? ☐ Outside of your state? ☐

Can you be an objective listener? Yes ☐ No ☐

Are you presently a member of SPOHNC? Yes ☐ No ☐

SPOHNC is sometimes contacted by market research companies on behalf of pharmaceutical companies looking to better serve diverse communities in their clinical trial design. These check off boxes may be relevant for those situations, which are often studies with compensation for participants. SPOHNC does not share or sell your personal information.

Race/ethnicity:

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic, Latino or Spanish Origin
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Multiethnic
- ☐ Prefer not to disclose
- ☐ Other ____________

To which gender identity do you most identify?

- ☐ Female
- ☐ Male
- ☐ Transgender female
- ☐ Transgender male
- ☐ Gender Variant/Nonconforming
- ☐ Not listed __________
- ☐ Prefer not to answer

EDUCATION, JOB EXPERIENCE AND COMMUNITY INVOLVEMENT

Education

High School Graduate ☐ Post-Graduate ☐

College Graduate ☐

Job Experience (explain briefly)____

____

Community Involvement (explain briefly)____

____

CANCER SPECIFIC INFORMATION

Relationship to patient____

Diagnosis Date____________________ Diagnosis____________________

General Anatomic site:		Specific site & Stage			Specific Site & Stage
Lip	☐	____________	Palate	☐	____________
Tongue	☐	____________	Nose	☐	____________
Floor of mouth	☐	____________	Paranasal sinuses	☐	____________
Salivary Gland	☐	____________	Cervical esophagus	☐	____________
Nasopharynx	☐	____________	Thyroid gland	☐	____________
Oropharynx	☐	____________	Oral cavity	☐	____________
Hypopharynx	☐	____________	Tonsil	☐	____________
Larynx (voice box)	☐	____________	Other	☐	____________
HPV	☐				

Treatment (briefly explain)____

Facility where patient received treatment?____

Surgery ☐

Neck Dissection ☐ ____

Feeding Tube ☐ For how long?____

Tracheotomy ☐ For how long?____

Laryngectomy ☐

Photodynamic Therapy ☐

Radiation Treatment

Standard	☐	Stereotactic	☐
IMRT	☐	Brachytherapy	☐
3D-CRT	☐	Hyperfractionated	☐
Neutron radiotherapy	☐	Proton therapy	☐

Chemotherapy ☐ Drugs used

Prior to radiation ☐ ____

During radiation ☐ ____

After radiation ☐ ____

ERBITUX ☐

Reconstructive Surgery ☐ Explain briefly____

____

____

Hyperbaric Oxygen Therapy ☐ Comment____

____

Acupuncture ☐ Comment____

____

Alternative/Complementary Medicine ☐ What kind?____

____

Special Dental Care____

____

Side Effects of Treatment

When did side effects begin? 3 weeks ☐ 6 weeks ☐ other ☐ ______________

Which side effects did you experience? Please check all that apply.

- Xerostomia (dry mouth) ☐
- Thick ropey saliva ☐
- Loss or change of taste ☐
- Mucositis ☐
- Bleeding in the mouth ☐
- Infections ☐
- Burning feeling of the tongue ☐
- Peeling of the tongue ☐
- Swelling of the tongue ☐
- Osteoradionecrosis ☐
- Swallowing difficulties ☐
- Weight loss ☐
- Trismus (difficulty opening ☐ the mouth) ☐
- Poor nutrition ☐
- Thrush ☐
- Fatigue ☐
- Impaired hearing ☐
- Skin changes ☐
- Dry eyes ☐
- Hair loss ☐
- Facial lymphedema ☐
- Stiffness in neck and jaw ☐
- Shoulder function ☐
- Hypothyroidism ☐
- Depression ☐
- Pain ☐
  - Where?________________
- Neurotoxicity ☐
- Nausea and vomiting ☐
- Dental problems ☐

How did the patient cope with side effects?

____

____

____

Products that the patient found helpful during/after treatment

Salagen	☐	Oralbalance	☐
Evoxac	☐	MouthKote	☐
Ethyol (Amifostine)	☐	Salivart	☐
Gelclaire	☐	Salix saliva tablets	☐
Biotene toothpaste	☐	Stoppers 4 Dry Mouth	☐
Biotene Mouthwash	☐	Toms Mouthwash from Maine	☐
Biotene Gum	☐		

Nutritional Supplements ☐ What kind?______________________________

Home Remedies
(Explain)____________________________________

Other____

Other:

Did the patient have a second opinion regarding diagnosis or treatment? Yes ☐ No ☐
Did the patient have any insurance issues? Yes ☐ No ☐

____

Please add any additional information that would tell us more about you and your interest in working with caregivers and other survivors.

Thank you.

If approved as a Volunteer, it is my intention to adhere to the standards and policies of Support for People with Oral and Head and Neck Cancer (SPOHNC). I will use all information and literature received from SPOHNC to further the best interests of oral and head and neck cancer survivors, caregivers and SPOHNC, P.O. Box 53, Locust Valley, NY 11560.

I understand that any information regarding survivors is privileged information to be used only for SPOHNC purposes and may not be duplicated or transmitted to others without written permission from the survivor or caregiver and SPOHNC. Should I resign as a Volunteer, I will return any survivor lists and materials to SPOHNC.

Signature____________________________________ Date____