

# Optic Neuropathy in Patients Treated with PD-1 Blockade

## Optic Neuropathy in Patients Treated with PD-1 Blockade

Thank you for your participation in this survey investigating immune checkpoint blockade inhibitors and the risk of optic neuropathy. We would like to identify patients who developed optic neuropathy after receiving one of several commercially available PD-1 or PD-L1 inhibitors for the treatment of cancer.

Please perform an EMR search of patients who have received any of the following drugs of interest, cross referenced with one of the following optic neuropathy diagnoses. We appreciate your filling out a survey for each patient identified.

Generic Name	Brand Name
Pembrolizumab	Keytruda
Nivolumab	Opdivo
Atezolizumab	Tecentriq
Avelumab	Bavencio
Durvalumab	Imfinzi
Ipilimumab [CTLA-4 inhibitor]	Yervoy

Disease	ICD-10 codes	ICD-9 codes
Optic neuritis / Optic neuropathy	H46.xxx	377.xxx
Cancer/melanoma associated retinopathy	H36	362.71, 362.72
Myasthenia gravis	G70.00	358.00
Inflammatory Orbitopathy/Thyroid-Like Ophthalmopathy	H05.10	376.11

This survey is estimated to take 15 minutes to complete if the patient's chart is readily available. The survey will query information related to demographics and clinical course and treatment. We recommend having the patient's chart available while completing the survey to facilitate data gathering. This survey can also be saved and returned to and completed later if needed.

At the end of the survey, there is an optional field in which you can provide your personal identification if you choose. We will use this information to acknowledge all physicians that have contributed to this project in any future publications. This information will not be used to track responses. Please leave this field blank if you choose to remain anonymous.

The results of this survey will be used for research (and is approved by the IRB board at UCLA) and participation is voluntary. Your responses are anonymous and will not be tracked back to you.

**Patient Demographic Information**

Patient age at time of diagnosis (years)

---

Gender

☐ Male ☐ Female

Race / Ethnicity

☐ White ☐ African American / Black ☐ American Indian / Alaska Native ☐ Asian / Pacific Islander  
☐ Hispanic / Latino ☐ Race/ethnicity unknown ☐ Other

---

(Other - please specify)

**Neuro-ophthalmic diagnosis**

Neuro-ophthalmic diagnosis

- ☐ Optic Neuritis / Optic papillitis / Swollen optic disc
- ☐ Optic Neuropathy
- ☐ Cancer / Melanoma Associated Retinopathy
- ☐ Myasthenia Gravis
- ☐ Inflammatory Orbitopathy / Thyroid-like Ophthalmopathy
- ☐ Other optic nerve disease

Other type of optic nerve disease observed, please describe clinical symptoms, treatment, and outcome.

ICD-10 / ICD-9 Diagnosis Code (if available)

\_\_\_\_\_

Unilateral vs Bilateral

- ☐ Unilateral   ☐ Bilateral

Date of diagnosis

\_\_\_\_\_

Date of resolution, if any

\_\_\_\_\_

**Optic Neuritis - Clinical Summary**

Type of optic neuritis

☐ Retrobulbar ☐ Intraocular ☐ Other

---

(Other - please specify)

---

Initial diagnosis or recurrence of optic neuritis

☐ Initial ☐ Recurrent

Signs/Symptoms present (select all that apply)

☐ Decreased visual acuity ☐ Pain with eye movement and/or periorbital discomfort ☐ Visual field defect  
☐ rAPD ☐ Color vision deficit ☐ Optic nerve swelling ☐ Other

---

(Other - please specify)

---

---

(Symptoms - any additional comments? )

---

Optic nerve exam (select all that apply)

☐ Normal exam ☐ Edema present ☐ Hemorrhages present ☐ Other

---

(Other - please specify)

---

---

(Exam - any additional comments?)

---

Grading of the optic nerve head edema if present (according to the Frisen Scale)

☐ Grade 1  
☐ Grade 2  
☐ Grade 3  
☐ Grade 4  
☐ Grade 5

**Optic Neuropathy - Clinical Summary**

Symptoms present (select all that apply)

☐ Decreased visual acuity   ☐ Visual field defect   ☐ rAPD   ☐ Color vision deficit   ☐ Other

---

---

(Other - please specify)

---

---

(Symptoms - any additional comments?)

---

Optic nerve exam (select all that apply)

☐ Normal exam   ☐ Edema present   ☐ Hemorrhages present   ☐ Atrophy present   ☐ Other

---

---

(Other - please specify)

---

---

(Exam - any additional comments?)

**Cancer / Melanoma Associated Retinopathy - Clinical Summary**

Type of Retinopathy

☐ Cancer associated   ☐ Melanoma associated   ☐ Other

---

---

(Other - please specify)

---

Symptoms Present (select all that apply)

☐ Decreased visual acuity   ☐ Flashes   ☐ Floaters   ☐ Photosensitivity   ☐ Nyctalopia  
☐ Visual field defect   ☐ Prolonged glare after light exposure   ☐ Prolonged dark adaptation  
☐ rAPD   ☐ Color vision deficit   ☐ Optic nerve swelling   ☐ Other

---

---

(Other - please specify )

---

---

(Symptoms - any additional comments?)

---

Fundus Exam Findings (select all that apply)

☐ Normal exam   ☐ Optic nerve pallor   ☐ Macular edema   ☐ RPE thinning and mottling  
☐ Attenuation of arterioles   ☐ Vitreous cells   ☐ Vascular sheathing   ☐ Periphlebitis  
☐ Other

---

---

(Other - please specify)

---

---

(Exam - any additional comments?)

---

**Myasthenia Gravis - Clinical Summary**

Signs/Symptoms Present (select all that apply)

- ☐ Ptosis   ☐ Diplopia   ☐ Strabismus   ☐ Issues with mastication   ☐ Issues with facial expression  
☐ Issues with speech   ☐ Issues with neck extensors   ☐ Issues with proximal limb muscle  
☐ Issues with respiratory muscles   ☐ Other

---

(Other - please specify)

---

---

(Symptoms - any additional comments? )

**Myasthenia Gravis - Diagnostic Testing**

	Positive	Negative	Not Performed
Edrophonium test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Repetitive nerve stimulation testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Single fiber EMG	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ice test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

(Diagnostic Testing - any additional comments? )

	Positive	Negative	Not Performed
Anti-ACh receptor antibody titer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Serum anti-muscle specific kinase antibody titer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

(Labs - any additional comments?)

---

Other Neuromuscular Junction related disease present?

☐ Yes   ☐ No

---

Please describe symptoms, treatment, and outcomes of any other neuromuscular disease.



**Inflammatory Orbitopathy / Thyroid-Like Ophthalmopathy - Clinical Summary**

Signs / Symptoms Present (select all that apply)

- ☐ Proptosis   ☐ Pain   ☐ Swelling   ☐ Erythema   ☐ Diplopia   ☐ Decreased vision   ☐ Visual field issues  
☐ Other

---

(Other - please specify)

---

---

(Symptoms - any additional comments?)

---

Exam Findings (select all that apply)

- ☐ Decreased vision   ☐ Color vision abnormalities   ☐ rAPD   ☐ Proptosis   ☐ Extraocular muscle restriction  
☐ Lid retraction   ☐ Lid lag   ☐ Lagophthalmos   ☐ Chemosis   ☐ Episcleritis   ☐ Scleritis  
☐ Optic nerve pallor   ☐ Other

---

(Other - please specify)

---

---

(Exam - any additional comments?)

**Visual Field**

Visual field defect if present (select all that apply)

- ☐ None   ☐ Altitudinal   ☐ Arcuate or partial arcuate   ☐ Central   ☐ Cecocentral scotoma  
☐ Enlarged blind spot   ☐ Diffuse visual field loss   ☐ Quadrant   ☐ Hemianopia   ☐ Three quadrant  
☐ Bitemporal hemianopia   ☐ Other

---

(Other - please specify)

---

---

(Visual Field - any additional comments?)

**Optic Neuritis - Additional Tests**

MRI Findings

Other white matter lesions present on brain MRI

☐ Yes ☐ No ☐ Unknown

Systemic neurologic findings associated with optic neuritis?

☐ Yes ☐ No

Please describe any associated systemic neurologic findings

	positive	negative	not performed
Anti-Aquaporin 4 antibody	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anti-MOG antibody	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Optic Neuropathy - Additional Tests

MRI / imaging findings

---

Additional tests and results

**Cancer / Melanoma Associated Retinopathy - Additional Tests**

Fundus Angiography Findings (select all that apply)

☐ Normal ☐ Leakage ☐ Macular edema ☐ Other

---

(Other - please specify)

---

---

(FA Findings - any additional comments?)

Optical Coherence Tomography (OCT) Findings (select all that apply)

☐ Normal ☐ Thinning ☐ Macular edema ☐ Other

---

(Other - please specify)

---

---

(OCT findings - any additional comments? )

Type of Electroretinogram (ERG) done

☐ Full field ERG ☐ Multifocal ERG ☐ Not performed

Electroretinogram (ERG) Findings (select all that apply)

☐ Normal ☐ Attenuated photopic response ☐ Absent photopic response ☐ Attenuated scotopic response ☐ Absent scotopic response ☐ Other

---

(Other - please specify)

---

---

(ERG Findings - any additional comments? )

---

**Laboratory Testing**

- ☐ None performed   ☐ Anti-retinal antibody positive   ☐ Anti-retinal antibody negative  
☐ Other
- 

---

(Other - please specify)

---

---

(Labs - any additional comments?)

**Inflammatory Orbitopathy / Thyroid-Like Ophthalmopathy - Additional Tests**

	Abnormal	Within normal limits	Not Performed
Complete blood count	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Basic metabolic panel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thyroid function studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Erythrocyte sedimentation rate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

	Positive	Negative	Not Performed
Anti-thyroid antibodies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anti-nuclear antibodies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anti-neutrophil cytoplasmic antibodies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rheumatoid factor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Angiotensin converting enzyme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rapid plasma reagin test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

---

(Labs - any additional comments?)

---

Imaging Performed (select all that apply)

☐ Computed tomography (OCT) optic nerve head   ☐ Magnetic resonance imaging   ☐ B-scan   ☐ Optical Coherence Tomography  
☐ Other   ☐ None performed

---

---

(Other - please specify)

---

Imaging Findings

**Treatment Details**

Treatment that patient received

Patient response to treatment

Clinical outcome



**Checkpoint Inhibitor Drug Information**

Which of the following drugs of interest was the patient administered? (select multiple if patient on combination therapy)

- ☐ Pembrolizumab (Keytruda)   ☐ Nivolumab (Opdivo)   ☐ Atezolizumab (Tecentriq)   ☐ Avelumab (Bavencio)   ☐ Durvalumab (Imfinzi)   ☐ Ipilimumab (Yervoy) [CTLA-4 inhibitor]   ☐ Other

\_\_\_\_\_  
(Other - please specify)

What was the drug dose and dosing regimen, if available?

\_\_\_\_\_

Date of first drug infusion

\_\_\_\_\_

Date of last drug infusion

\_\_\_\_\_

What was the clinical indication for the drug of interest (concurrent cancer diagnosis)?

- ☐ Malignant melanoma   ☐ Hodgkin's lymphoma   ☐ Non small cell lung cancer   ☐ Squamous cell carcinoma of head and neck   ☐ Urothelial carcinoma   ☐ Renal cell carcinoma   ☐ Merkel cell carcinoma  
☐ Microsatellite instability high or mismatch repair deficient metastatic cancer   ☐ Other

\_\_\_\_\_  
(Other - please specify)

**Physician Identification (optional)**

If you would like to be acknowledged for your contribution to this research project, please provide your full name, email address, and city. This will not be used to track information. If you would like to remain anonymous, please leave this field blank.

---

If you have any feedback related to this survey or research project, please provide feedback here.