Demographics

Demographics Information

Study Subject ID

_____
(Example: PYA1, or RUP2. The first letter will be either P (Prospective) or R (Retrospective). The next two letters are center codes that have been assigned to you, for example YA for Yale. The No. is the subject No. at your site. Please make a note of this No. in relationship to you patient's ID No., so you can identify the patient. Also, if your patient has multiple TPE series, please make sure that you use the same Study subject ID No.))

Center ID

◯ Cleveland Clinic (CC)
◯ CHOP (CH)
◯ CNMC (CN)
◯ Columbia (CO)
◯ Mayo (MA)
◯ New York Blood Center (NY)
◯ U Minn (UM)
◯ U Penn (UP)
◯ U Michigan (MI)
◯ Virginia Commonwealth University (VC)
◯ Yale (YA)

Gender

◯ Female
◯ Male
◯ Undifferentiated
◯ Unknown

Ethnicity

◯ Hispanic or Latino
◯ Not Hispanic or Latino

Race

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Unknown or mixed
(Study participants should self-report race, with race being asked about after ethnicity. Check all that apply.)

What is the subject's age at the first Study TPE

_____
(Record age of the subject in years. Ex: 39 or 45.)

What is the subject's age at initial NMO diagnosis

_____
(Record age of the subject in years. Ex: 39 or 45.)

Year of the first study TPE performed/Started

◯ 2017
◯ 2016
◯ 2015
◯ 2014
◯ 2013
◯ 2012
◯ 2011
◯ 2010
◯ 2009
◯ 2008
◯ 2007
◯ 2006
◯ 2005
◯ 2004
◯ 2003
◯ 2002
◯ 2001
◯ 2000

(Year of the first TPE procedure performed for this TPE session)

Prior non-registered TPE

◯ Yes
◯ No

(If there are prior TPE sessions that you are aware, but you do not intend to report to the registry or the TPE were performed prior to 2000, please check yes for this field, and give a brief summary below of the prior TPEs such as roughly when, what for, the estimated No., outcome, and source of the information such as per chart, per patient, per family, etc.)

Notes for prior non-registered TPE

_____

(If there are prior TPE session that you are aware, but you do not intend to report to the registry or the TPE were performed prior to 2000, please give a brief summary of the prior TPEs such as roughly when, what for, the estimated No., outcome, and source of the information such as per chart, per patient, per family, etc.)

Study Enrollment Date

_____

(Please enter the date that you start to work on this case, so you can obtain a summary for IRB reporting)

What is the date of complete reporting?

_____

((Please enter the date of your completion of this case.))

Study notes

_____

((Please use this field to leave notes for your own use or notes for the registry committee)

TPE Session Info neuromyelitis Optica

TPE Session Information Please provide summary for this TPE session

What study TPE series Is this?

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ >10, please enter No. below
(This refers to a series of TPE treatments, defined by the referral orders)

Total Series No. if >10, otherwise, leave it blank

_____

Overall how many treatment series has this patient gone through?

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ >10, please enter No. below

No. if >10, otherwise, leave it blank

_____

Date of first TPE in this TPE series/session

_____
(Date for the first TPE for this TPE series or session)

Date of last TPE in this TPE series/session

_____

Weight (Kg)

_____

Height (cm)

_____

Diagnostic Criteria□□In addition to optic neuritis and transverse myelitis, two of the three following must be present.

☐ Optic neuritis
☐ Transverse Myelitis
☐ Brain MRI normal or nonspecific white matter lesions*
☐ Spinal cord MRI showing lesion extending over 3 or more continguous vertebral segments*
☐ NMO-IgG seropositivity*
(Please check all apply)

Clinical symptoms at Onset (before start of first TPE of this series)

- ☐ Simultaneous or separate onset of optic neuritis and acute transverse myelitis
- ☐ Blindness (Optic neuritis)
- ☐ Paraparesis (Transverse myelitis)
- ☐ Bilateral sensory loss (Transverse myelitis)
- ☐ Sphinctor dysfunction (Transverse myelitis)
- ☐ Radicular pain (Transverse myelitis)
- ☐ Paroxysmal spasms (Transverse myelitis)
- ☐ Nausea and vomiting (Brainstem/Hypothalamic)
- ☐ Vertigo(Brainstem/Hypothalamic)
- ☐ Hearing loss(Brainstem/Hypothalamic)
- ☐ Facial weakness(Brainstem/Hypothalamic)
- ☐ Trigeminal neuralgia(Brainstem/Hypothalamic)
- ☐ Diplopia(Brainstem/Hypothalamic)
- ☐ Nystagmus(Brainstem/Hypothalamic)
- ☐ Intractable hiccups(Brainstem/Hypothalamic)
- ☐ Respiratory failure(Brainstem/Hypothalamic)
- ☐ Endocrine dysfunction(Brainstem/Hypothalamic)

Treatment summary

- ◯ Steroid resistant add on
- ◯ Steroid + TPE combination treatment de novo
- ◯ Maintenance
- ◯ Others

Treatment summary notes

_____

Clinical status assessment (from pre-TPE baseline to within 10 days post last TPE)

- ◯ 1-No improvement
- ◯ 2-Mild improvement (slight but definite change and with no impact on the daily function)
- ◯ 3-Moderate improvement (obvious improvement that impacts daily function)
- ◯ 4-Marked improvement (significant difference from Pre-first TPE baseline with major functional daily improvement)
- ◯ 5-full recovery from Pre-first TPE baseline

Did patient relapse after this TPE series/session?

- ◯ Yes
- ◯ No

If patient relapsed after this TPE series/session, age (yrs) at relapsed:

_____

If patient relapsed after this TPE series/session, months lapsed since last TPE:

_____

Meds tried prior to start of TPE

- ☐ Prednisone
- ☐ Methylprednisolone
- ☐ Hydrocortisone
- ☐ IVIG
- ☐ Rituximab
- ☐ Avonex
- ☐ Glatiramer acetate
- ☐ Cyclophosphamide
- ☐ Natalizumab
- ☐ Mitoxantrone
- ☐ Methotrexate
- ☐ Azathioprine
- ☐ Mycophenolate
- ☐ Mofetil
- ☐ Other

Meds while on TPE

- ☐ Prednisone
- ☐ Methylprednisolone
- ☐ Hydrocortisone
- ☐ IVIG
- ☐ Rituximab
- ☐ Avonex
- ☐ Glatiramer acetate
- ☐ Cyclophosphamide
- ☐ Natalizumab
- ☐ Mitoxantrone
- ☐ Methotrexate
- ☐ Azathioprine
- ☐ Mycophenolate
- ☐ Mofetil
- ☐ Other

Meds within 0-10 days post last TPE

- ☐ Prednisone
- ☐ Methylprednisolone
- ☐ Hydrocortisone
- ☐ IVIG
- ☐ Rituximab
- ☐ Avonex
- ☐ Glatiramer acetate
- ☐ Cyclophosphamide
- ☐ Natalizumab
- ☐ Mitoxantrone
- ☐ Methotrexate
- ☐ Azathioprine
- ☐ Mycophenolate
- ☐ Mofetil
- ☐ Other

Meds within 11-30 days post last TPE

- ☐ Prednisone
- ☐ Methylprednisolone
- ☐ Hydrocortisone
- ☐ IVIG
- ☐ Rituximab
- ☐ Avonex
- ☐ Glatiramer acetate
- ☐ Cyclophosphamide
- ☐ Natalizumab
- ☐ Mitoxantrone
- ☐ Methotrexate
- ☐ Azathioprine
- ☐ Mycophenolate
- ☐ Mofetil
- ☐ Other

Meds within 31-60 days post last TPE

- ☐ Prednisone
- ☐ Methylprednisolone
- ☐ Hydrocortisone
- ☐ IVIG
- ☐ Rituximab
- ☐ Avonex
- ☐ Glatiramer acetate
- ☐ Cyclophosphamide
- ☐ Natalizumab
- ☐ Mitoxantrone
- ☐ Methotrexate
- ☐ Azathioprine
- ☐ Mycophenolate
- ☐ Mofetil
- ☐ Other

Meds Status Assessment, please assess status from pre_TPE baseline to within 30 days post last TPE

	No Change	Decreased	Stopped	Increased	Added
Prednisone	◯	◯	◯	◯	◯
Methylprednisolone	◯	◯	◯	◯	◯
Hydrocortisone	◯	◯	◯	◯	◯
IVIG	◯	◯	◯	◯	◯
Rituximab	◯	◯	◯	◯	◯
Avonex	◯	◯	◯	◯	◯
Betaseron	◯	◯	◯	◯	◯
Glatiramer acetate	◯	◯	◯	◯	◯
Cyclophosphamide	◯	◯	◯	◯	◯
Natalizumab	◯	◯	◯	◯	◯
Mitoxantrone	◯	◯	◯	◯	◯
Methotrexate	◯	◯	◯	◯	◯
Azathioprine	◯	◯	◯	◯	◯
Mycophenolate	◯	◯	◯	◯	◯
Mofetil	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯

Meds Status Assessment, please assess status from pre_TPE baseline to within 60 days post last TPE

	No Change	Decreased	Stopped	Increased	Added
Prednisone	◯	◯	◯	◯	◯
Methylprednisolone	◯	◯	◯	◯	◯
Hydrocortisone	◯	◯	◯	◯	◯
IVIG	◯	◯	◯	◯	◯
Rituximab	◯	◯	◯	◯	◯
Avonex	◯	◯	◯	◯	◯
Glatiramer acetate	◯	◯	◯	◯	◯
Cyclophosphamide	◯	◯	◯	◯	◯
Natalizumab	◯	◯	◯	◯	◯
Mitoxantrone	◯	◯	◯	◯	◯
Methotrexate	◯	◯	◯	◯	◯
Azathioprine	◯	◯	◯	◯	◯
Mycophenolate	◯	◯	◯	◯	◯
Mofetil	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯

Replacement solution predominantly used

- ☐ 5% albumin
- ☐ Plasma protein fraction/plasmanate
- ☐ FFP
- ☐ Plasma >24 hrs thawed
- ☐ Normal Saline
- ☐ Hetastarch
- ☐ Others

If another solution was used other than albumin/plasmanate was it because of:

- ☐ Possible coagulopathy
- ☐ It is standard protocol at my institution
- ☐ Availability of primary product
- ☐ Patient preference
- ☐ Possible transfusion reaction
- ☐ Other

(Please check all apply)

If Other, please explain:

_____

Volume of exchange (average):

- ◯ < 1 plasma volume
- ◯ 1.0-1.25
- ◯ 1.26 -1.50
- ◯ 1.51-1.75
- ◯ 1.76-2.00
- ◯ 2.01-3.0
- ◯ >3.0

Frequency of exchange

- ◯ Daily
- ◯ Every other day including weekends
- ◯ Every other day, not including weekends
- ◯ Once a week
- ◯ Twice a week
- ◯ Weekly
- ◯ Every other week
- ◯ Every three weeks
- ◯ Monthly
- ◯ Every two months
- ◯ Other

Others, please detail

_____

For others, please detail _____

Notes for TPE session

_____

TPE Procedure Information

Start date of this TPE Procedure

_____

Global Neurological Assessment (baseline or since last TPE)

◯ Baseline-First TPE
◯ 1-No improvement
◯ 2-Mild improvement (slight but definite change and with no impact on the daily function)
◯ 3-Moderate improvement (obvious improvement that impacts daily function)
◯ 4-Marked improvement (significant difference from Pre-first TPE baseline with major functional daily improvement)
◯ 5-full recovery from Pre-first TPE baseline
(Comparing to pre-first TPE baseline)

Plasma Volume Exchanged for This TPE Procedure

◯ < 0.75 plasma volume
◯ 0.76-0.99
◯ 1.0-1.25
◯ 1.26 -1.50
◯ 1.51-1.75
◯ 1.76-2.00
◯ 2.10-2.50
◯ >2.5
◯ Others
(Plasma volume (No. exchanged), such as 1, 1.5, 2)

Notes for Volume exchanged

_____
(If you answered "others" on the above question, please specify here)

Fluid Balance

◯ 100%
◯ 105%
◯ 110%
◯ 95%
◯ Others: Please type in notes

Notes for Fluid balance

_____
(If you answered "others" on the above question, please specify here)

Replacement Fluid 1

◯ 5% albumin
◯ Plasma protein fraction/plasmanate
◯ FFP
◯ Plasma >24 hrs thawed
◯ Normal Saline
◯ Hetastarch
◯ Others
(If your fluid is not listed, please use replacement fluid 3)

Notes for Replacement Fluid 1

_____
(If you answered "others" on the above question, please specify here)

Replacement Fluid 1 Volume (ml)

_____
(mL)

Replacement Fluid 2

◯ 5% albumin
◯ Plasma protein fraction/plasmanate
◯ FFP
◯ Plasma >24 hrs thawed
◯ Normal Saline
◯ Hetastarch
◯ Others

Notes for Replacement Fluid 2

_____
(If you answered "others" on the above question, please specify here)

Replacement Fluid 2 Volume (mL)

_____
(mL)

Replacement Fluid 3

◯ 5% albumin
◯ Plasma protein fraction/plasmanate
◯ FFP
◯ Plasma >24 hrs thawed
◯ Normal Saline
◯ Hetastarch
◯ Others
(plasma, 5% albumin, etc.)

Replacement 3 notes

_____
(If you answered "others" on the above question, please specify here)

Replacement Fluid 3 Volume (ml)

_____
(mL)

Access

◯ Peripheral access
◯ IJ central line
◯ SC central line
◯ Femoral line
◯ Permacath
◯ Fistula
◯ Others

Access notes

_____
(If access type is not listed, please specify)

Anticoagulant used for TPE

◯ ACD-A
◯ ACD/Heparin
◯ Heparin
◯ Others

Anticoagulant notes

_____
(If anticoagulant is not listed, please specify)

Calcium replacement

☐ Add Ca into replacement fluid
☐ i.v. Ca continuous infusion
☐ p.o. Ca
☐ i.v. and p.o. Ca
☐ None
☐ Others, please specify in notes

Ca replacement notes

_____
(If you answered "others" on the above question, please specify here)

Potassium Replacement

◯ Yes
◯ No

Magnesium Replacement

◯ Yes
◯ No

RBC priming performed

◯ Yes
◯ No

Rinseback Performed

☐ None
☐ Partial
☐ Full

BPsystolic pre _____

BPdiastolic, pre _____

HR pre _____

Temp (F), pre _____

Temp (C), pre _____

O2 Sat % pre _____

Oxygen Treatment, pre
◯ RA
◯ 2L, face mask
◯ 4L, face mask
◯ Mechanic Ventilation
◯ Others

Notes for Oxygen treatment, pre _____
(If you answered "others" on the above question, please specify here)

BPsystolic, post _____

BPdiastolic, post _____

HR, post _____

Temp (F), post _____

Temp (C), post _____

O2 Sat %, post _____

Oxygen, treatment post
◯ RA
◯ 2L, face mask
◯ 4L, face mask
◯ Mechanic Ventilation
◯ Others

Notes for Oxygen treatment, post _____
(If you answered "others" on the above question, please specify here)

Apheresis Adverse event
◯ yes
◯ no
◯ others
(If answered yes or others, please fill the next two sections)

Please define the imputability and severity of the adverse reaction:

Imputability:
Definitively: The only explanation
Probable: The likelihood is high, but not absolute
Possible: The likelihood is relatively high, but it is also possible not relate to apheresis
Can't rule out: The likelihood is very small, but not impossible
Not related: not related to apheresis

Severity:
None
Mild: no or minor modification of procedure
Moderate: major modification including stopping of procedure
Severe: patient was admitted or received major medical treatment or death

Apheresis Adverse Reaction

	Definitively	Probable	Possible	Can't rule out	Not related	Mild	Moderate	Severe
Vasovagal reaction	☐	☐	☐	☐	☐	☐	☐	☐
Citrate toxicity	☐	☐	☐	☐	☐	☐	☐	☐
Hypovolemia	☐	☐	☐	☐	☐	☐	☐	☐
Blood not returned	☐	☐	☐	☐	☐	☐	☐	☐
Others	☐	☐	☐	☐	☐	☐	☐	☐

If answered others, please note here

_____

Transfusion reaction present?

◯ No
◯ Yes, please report in detail
◯ Others, please report in detail

Please define type, imputability and severity of transfusion reaction:

Please use CDC definition

[Attachment: "BV-HV-protocol-current.pdf"]

TPE Procedure Notes

_____

(Please use this field to write note for yourself or to the registry)

TPE Labs

Labs during TPE session/series

Date of Lab _____

Time to TPE
◯ 12-24 hrs prior to starting TPE
◯ < 12 hrs prior to starting TPE
◯ During TPE
◯ Within 12 hrs after finishing TPE
◯ 12-24 hrs after finishing TPE

PT (sec) _____

INR _____

PTT (sec) _____

Fibrinogen (mg/dL) _____

Hct (%) _____

Hemoglobin (g/dL) _____

Platelet (K/microL) _____

Albumin (g/dL) _____

Total Protein (g/dL) _____

Creatinine (mg/dL) _____

Ca (mg/dL) _____

Mg (mg/dL) _____

Phos (mg/dL) _____

iCa _____

iCa units
◯ mg/dL
◯ mmol/L

Notes of Labs if necessary

_____

NMO Labs

Date of NMO labs _____

Data Type
- ◯ Baseline (before current attack)
- ◯ During Attack (pre-medical treatment, as many as you have)
- ◯ Before first TPE for this session (closest one)
- ◯ During TPE (as many as you have)
- ◯ Post TPE within 1 month
- ◯ Post TPE between 1 and 3 months
- ◯ Post TPE between 3 and 6 months

Time to TPE if during TPE session
- ◯ 12-24 hrs prior to starting TPE
- ◯ < 12 hrs prior to starting TPE
- ◯ During TPE
- ◯ Within 12 hrs after finishing TPE
- ◯ 12-24 hrs after finishing TPE
- ◯ N/A

NMO-IgG, Serum
- ◯ Positive
- ◯ Negative
- ◯ Not Done

NMO/AQP4-IgG ELISA, Serum performed?
- ◯ Yes
- ◯ No

Value of Aquaphorin Antibody (U/mL) _____
(Normal (< 1.6 U/mL))

Source of testing (research lab/certified reference lab) _____

Other antibodies positive?
- ◯ Yes
- ◯ No
- ◯ Not Done

Name of other antibody (first one) _____

Positivity/Titer (antibody above) _____

Source of testing (research lab/certified reference lab) Other 1: _____

Name of other antibody (second one) _____

Positivity/Antibody Titer (second one) _____

Source of testing (research lab/certified reference lab) (second one): _____

For other positive antibodies, describe type, date of testing, titer/results, labortory sourse as above _____

CSF oligoclonal IgG bands
- ◯ Negative
- ◯ Positive
- ◯ Not performed
- ◯ Others, please specify in comments

CSF leukocytosis
- ◯ Present
- ◯ Absent
- ◯ Not performed
- ◯ Others, please specify in comments

NMO lab notes

TPE NMO Clinical Assessment

NMO Clinical Assessment If possible please collect baseline (before current NMO attack), during attack (before any treatment as well as before TPE treatment), pre-TPE baseline, during TPE (as many as you can), about 6 month post TPE

Date of NMO Clinical Assessment _____

Data type

◯ Baseline (before current attack)
◯ During Attack (pre-medical treatment, as many as you have)
◯ Before first TPE for this session (closest one)
◯ During TPE (as many as you have)
◯ Post TPE within 1 month
◯ Post TPE between 1 and 3 months
◯ Post TPE between 3 and 6 months

Clinical symptoms

☐ Simultaneous or separate onset of optic neuritis and acute transverse myelitis
☐ Blindness (Optic neuritis)
☐ Paraparesis (Transverse myelitis)
☐ Bilateral sensory loss (Transverse myelitis)
☐ Sphincter dysfunction (Transverse myelitis)
☐ Radicular pain (Transverse myelitis)
☐ Paroxysmal spasms (Transverse myelitis)
☐ Nausea and vomiting (Brainstem/Hypothalamic)
☐ Vertigo (Brainstem/Hypothalamic)
☐ Hearing loss (Brainstem/Hypothalamic)
☐ Facial weakness (Brainstem/Hypothalamic)
☐ Trigeminal neuralgia (Brainstem/Hypothalamic)
☐ Diplopia (Brainstem/Hypothalamic)
☐ Nystagmus (Brainstem/Hypothalamic)
☐ Intractable hiccups (Brainstem/Hypothalamic)
☐ Respiratory failure (Brainstem/Hypothalamic)
☐ Endocrine dysfunction (Brainstem/Hypothalamic)
☐ Other-document in notes
(Check all apply)

Meds/treatment on

☐ Prednisone
☐ Methylprednisolone
☐ Hydrocortisone
☐ IVIG
☐ Rituximab
☐ Avonex
☐ Glatiramer acetate
☐ Cyclophosphamide
☐ Natalizumab
☐ Mitoxantrone
☐ Methotrexate
☐ Azathioprine
☐ Mycophenolate
☐ Mofetil
☐ Other-document in notes

Data Source

◯ Extraction from neurology notes
◯ Extraction from clinical notes
◯ Own assessment
◯ Others

Initial of the Person who did the data extraction _____

Notes for meds/treatment

NMO-Image studies

Date of Imaging Studies _____

Data Type

- ◯ Baseline (before current attack)
- ◯ During Attack (pre-medical treatment, as many as you have)
- ◯ Before first TPE for this session (closest one)
- ◯ During TPE (as many as you have)
- ◯ Post TPE within 1 month
- ◯ Post TPE between 1 and 3 months
- ◯ Post TPE between 3 and 6 months

Image type

- ◯ MRI
- ◯ CT
- ◯ X-Ray
- ◯ Ultrasounds
- ◯ Others-comment in motes

Image result summary

_____

Image result notes

_____

Expanded Disability Status Scale

Expanded Disability Status Scale: If possible please collect baseline (before current NMO attack), during attack (before any treatment as well as before TPE treatment), pre-TPE baseline, during TPE (as many as you can), about 6 month post TPE

Date of EDSS assessment _____

Data Type

- ◯ Baseline (before current attack)
- ◯ During Attack (pre-medical treatment, as many as you have)
- ◯ Before first TPE for this session (closest one)
- ◯ During TPE (as many as you have)
- ◯ Post TPE within 1 month
- ◯ Post TPE between 1 and 3 months
- ◯ Post TPE between 3 and 6 months

Disability Scale

- ◯ 0.0 - Normal neurological exam (all grade 0 in all Functional System [FS] scores*
- ◯ 1.0 - No disability, minimal signs in one FS* (i.e., grade 1).
- ◯ 1.5 - No disability, minimal signs in more than one FS* (more than 1 FS grade 1)
- ◯ 2.0 - Minimal disability in one FS (one FS grade 2, others 0 or 1).
- ◯ 2.5 - Minimal disability in two FS (two FS grade 2, others 0 or 1)
- ◯ 3.0 - Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three or four FS grade 2, other 0 or 1) though fully ambulatory.
- ◯ 3.5 - Fully ambulatory but with moderate disability in one FS (one grade 3) and one or two FS grade 2; or two FS grade 3 (others 0 or 1) or five grade 2 (others 0 or 1)
- ◯ 4.0 - Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade (others 0 or 1), or combination of lesser grades exceeding limits of previous steps; able to walk without aide or rest some 500 m
- ◯ 4.5 - Fully ambulatory without aide, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity of require minimal assistance; characterized by relatively severe disability usually consisting of one FS grade 4 (others 0 or 1) or combinations of less grades exceeding limits of previous steps; able to walk without aid or rest some 300 meters
- ◯ 5.0 - Ambulatory without aid or rest for about 200 meters; disability severe enough to impair full daily activities (e.g., to work a full day without special provisions); (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding specification for step 4.0).
- ◯ 5.5 - Ambulatory without aide for about 100 meters; disability severe enough to preclude full daily activities; (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding those for step 4.0)
- ◯ 6.0 - Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 meters with or without resting; (Usual FS equivalents are combination with more than two FS grade 3+)
- ◯ 6.5 - Constant bilateral assistance (canes, crutches, braces) required to walk about 20 meters without resting; (Usual FS equivalents are combinations with more than two FS grade 3+)
- ◯ 7.0 - Unable to walk beyond approximately 5 meters even with aid, essentially restricted to wheelchair, wheels self in standard wheelchair and transfers alone; up and about in wheel chair some 12 hours a day (Usual FS equivalents are combination with more than on e FS grad 4+; very rarely pyramidal grade 5 alone)
- ◯ 7.5 - Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; May require motorized wheelchair; (Usual FS equivalents are combination with more than one FS grade 4+)
- ◯ 8.0 - Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much for the day; retains many self-care functions; generally has effective use of arms;

(Usual FS equivalents are combinations, generally 4+ in several systems).

◯ 8.5 - Essential restricted to bed much of day; has some effect use of arm(s); retains some self-care functions; (Usual FS equivalents are combinations, generally 4+ in several systems).

◯ 9.0 - Helpless bed patient; can communicate and eat; (Usual FS equivalents are combinations, mostly grade 4+)

◯ 9.5 - Totally helpless bed patient; unable to communicate effectively or eat/swallow; (Usual FS equivalents are combinations, almost all grade 4+)

◯ 10.0 - Death due to NMO

(*excludes cerebral function grade 1 Note 1: EDSS steps 1.0 to 4.5 refer to patients who are fully ambulatory and the precise step number is defined by the Function System score(s). EDSS steps 5.0 to 9.5 are defined by the impairment to ambulation and usual equivalents in Functions Systems scores are provided. Note 2: EDSS should not change by 1.0 step unless there is a change in the same director of at least one step in at least one FS.)

EDSS notes

_____

Opticospinal Impairment Score Osis

Opticospinal Impairment Score Osis If possible please collect baseline (before current NMO attack), during attack (before any treatment as well as before TPE treatment), pre-TPE baseline, during TPE (as many as you can), about 6 month post TPE

Date of OSIS Filled Out

_____
(Date of OSIS performed)

Data Type

◯ Baseline (before current attack)
◯ During Attack (pre-medical treatment, as many as you have)
◯ Before first TPE for this session (closest one)
◯ During TPE (as many as you have)
◯ Post TPE within 1 month
◯ Post TPE between 1 and 3 months
◯ Post TPE between 3 and 6 months

Visual acuity (VA)

◯ 0 Normal
◯ 1 Scotoma but VA (corrected) better than 20/30
◯ 2 VA 20/30-20/59
◯ 3 VA 20/60 - 20/100
◯ 4 VA 20/101 - 20/200
◯ 5 VA 20/201 - 20/800
◯ 6 Count fingers only
◯ 7 Light perception only
◯ 8 No light perception

Motor Function

◯ 0 Normal
◯ 1 Abnormal signs (hyperreflexia, Babinski sign) without weakness
◯ 2 Mild weakness (MRC grade 5- or 4+) in affected limb (s)
◯ 3 Moderate weakness (grade 3 or 4) in 1 or 2 UMN muscles in affected limb(s)
◯ 4 Moderate weakness (grade 3 or 4) in 3 UMN muscles in affected limbs(s)
◯ 5 Severe weakness (grade 2) in 1 or more muscles in affected limb(s)
◯ 6 Some plegic (grade 0 or 1) muscles in 1 or more limbs
◯ 7 Plegia (grade 0 or 1) of all muscles in 1 or more limbs

Sensory Function

◯ 0 Normal
◯ 1 Mild decrease in vibration
◯ 2 Mild decrease in pinprick/temperature/proprioception or moderate decrease in vibration
◯ 3 Moderate decrease in touch/pin/proprioception or essentially lost vibration sense
◯ 4 Loss of all sensory modalities
◯ 5 Unknown

Sphincter Function

- ◯ 0 Normal
- ◯ 1 Mild urinary urgency or hesitancy; constipation
- ◯ 2 Moderate urinary urgency, hestancy, retention of blader or bowel, infrequent urinary incontinence (less than once/week)
- ◯ 3 Frequent incontinence or retention requiring intermittent bladder catheterizatin or aggressive (manual) bowel assistance
- ◯ 4 Indwelling urinary catheter or absence of sphincter control
- ◯ 5 Unknown

Total Score of OSIS _____

OSIS notes

_____

Hauser Ambulation Index

Hauser Ambulation Index If possible please collect baseline (before current NMO attack), during attack (before any treatment as well as before TPE treatment), pre-TPE baseline, during TPE (as many as you can), about 6 month post TPE

Date of Hauser Index Filled out

_____
(Please enter date of Hauser Index performed)

Data Type

- ◯ Baseline (before current attack)
- ◯ During Attack (pre-medical treatment, as many as you have)
- ◯ Before first TPE for this session (closest one)
- ◯ During TPE (as many as you have)
- ◯ Post TPE within 1 month
- ◯ Post TPE between 1 and 3 months
- ◯ Post TPE between 3 and 6 months

*The use of a wheelchair may be determined by lifestyle and motivation. It is expected that patients in Grade 7 will use a wheelchair more frequently than those in Grades 5 or 6. Assignment of a grade in the range of 5 to 7, however, is determined by the patient's ability to walk a given distance, and not by the extent to which the patient uses a wheelchair.

- ◯ 0 Asymptomatic; fully active
- ◯ 1 Walks normally, but report fatigue that interferes with athletic or other demanding activities
- ◯ 2 Abnormal gait or episodic imbalance; gait disorder is noticed by family and friends; able to walk 25 feet (8 meters) in 10 seconds or less
- ◯ 3 Walks independently; able to walk 25 feet in 20 seconds or less
- ◯ 4 Requires unilateral support (cane or single crutch) to walk; walks 25 feet in 20 seconds or less
- ◯ 5 Requires bilateral support (canes, crutches, or walker) and walks 25 feet in 25 seconds or less; or requires unilateral support but needs more than 20 seconds to walk 25 feet.
- ◯ 6 Requires bilateral support and more than 20 seconds to walk 25 feet; may use wheelchair* on occasion
- ◯ 7 Walking limited to several steps with bilateral support; unable to walk 25 feet; may use wheelchair* for most activities
- ◯ 8 Restricted to wheelchair; able to transfer self independently
- ◯ 9 Restricted to wheelchair; unable to transfer self independently

Hauser Index note

_____

Quality Of Life

Date Quality of Life Questionnaire Performed

_____
(Please enter Date Quality of Life Questionnaire performed)

Data Type

◯ Baseline (before current attack)
◯ During Attack (pre-medical treatment, as many as you have)
◯ Before first TPE for this session (closest one)
◯ During TPE (as many as you have)
◯ Post TPE within 1 month
◯ Post TPE between 1 and 3 months
◯ Post TPE between 3 and 6 months

In most ways my life is close to my ideal

◯ Strongly Disagree (1 pt)
◯ Disagree (2 pts)
◯ Slightly Disagree (3 pts)
◯ Neither Agree or Disagree (4 pts)
◯ Slightly Agree (5 pts)
◯ Agree (6 pts)
◯ Strongly Agree (7 pts)
(To be answered by participant)

The conditions of my life are excellent

◯ Strongly Disagree (1 pt)
◯ Disagree (2 pts)
◯ Slightly Disagree (3 pts)
◯ Neither Agree or Disagree (4 pts)
◯ Slightly Agree (5 pts)
◯ Agree (6 pts)
◯ Strongly Agree (7 pts)
(To be answered by participant)

I am satisfied with life

◯ Strongly Disagree (1 pt)
◯ Disagree (2 pts)
◯ Slightly Disagree (3 pts)
◯ Neither Agree or Disagree (4 pts)
◯ Slightly Agree (5 pts)
◯ Agree (6 pts)
◯ Strongly Agree (7 pts)
(To be answered by participant)

So far I have gotten the important things I want in life

◯ Strongly Disagree (1 pt)
◯ Disagree (2 pts)
◯ Slightly Disagree (3 pts)
◯ Neither Agree or Disagree (4 pts)
◯ Slightly Agree (5 pts)
◯ Agree (6 pts)
◯ Strongly Agree (7 pts)
(To be answered by participant)

If I could live my life over, I would change almost nothing

◯ Strongly Disagree (1 pt)
◯ Disagree (2 pts)
◯ Slightly Disagree (3 pts)
◯ Neither Agree or Disagree (4 pts)
◯ Slightly Agree (5 pts)
◯ Agree (6 pts)
◯ Strongly Agree (7 pts)
(To be answered by participant)

Final Score for Quality Of Life

_____

Notes for Quality of Life Questionnaire

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