You are being invited to participate in a research study. Before you take part in this, the study must be explained to you thoroughly and you must be given the chance to ask questions about it. Please read carefully. If you agree to participate, please sign the informed consent form. After signing, you will be given a copy of this document. You will then be asked to answer 11 Yes-No questions which would screen you for X-linked dystonia-parkinsonism.

Screening Questionnaire in English
Patient ID:
Age:
Date:
INTERVIEW PROPER: Answer with either YES or NO
Dystonia Questions
Do you experience sustained twisting movements of any body part?
Do you experience constant tongue protrusion and retraction?
Do you experience constant jaw opening and closing?
Do you find any of your body parts shifting, tilting or turning in any direction?
Has anyone told you that any of your body parts seem to be twisting in different directions?
Parkinson’s Disease Questions
Do you experience slowness in movement?
Do you experience tremors in your hands while they are at rest?
Have you noticed stiffness in your arms or legs?
Do you shuffle your feet or take smaller steps when you walk?
Has your doctor or anyone you know told you that you have lubag or dystonia parkinsonism?
Do you have brothers, sisters or parents who have been told they have lubag or dystonia parkinsonism?

Screening Questionnaire in Hiligaynon
Patient ID:
Age:
Date:
INTERVIEW PROPER: Tubag lang kung OO o DILI
Dystonia Questions
Kabatyag bala ikaw nga may parte sang imo lawas nga naga-lubag?
Kabatyag bala ikaw nga sige guwa-sulod ang imo dila?
Kabatyag bala ikaw ang pirmi nga pag-nganga kag pagkipot sang imo baba?
Kabatyag bala ikaw nga naga-gihon, naga-takilid, ukon naga-liso ang mga parte sang imo lawas?
May nakahambal bala sa imo nga may mga parte sang imo lawas nga naga-liso ukon naga-lubag?
Parkinson’s Disease Questions
Kabatyag ka nga naga-hinay ang imo pag-giho?
Kabatyag ka nga kurog ang imo nga kamot biskan nga-pahuway?
Kabatyag ka sang palanig^-a sang imo mga butkon ukon mga tiil?
Kabatyag ka nga naga-gamay ang imo tikang kung maglakat ka?
May naka-hambal bala sa imo nga doktor ukon biskan sin^-o nga may lubag ka ukon dystonia parkinsonism nga ginatawag?
May mga utod ukon ginikanan bala ikaw nga nahambalan nga may lubag ukon dystonia parkinsonism nga ginatawag?
PATIENT INFORMATION SHEET AND INFORMED CONSENT FORM (ENGLISH)

You are being invited to participate in a research study. Before you take part in this, the study must be explained to you thoroughly and you must be given the chance to ask questions about it. Please read carefully. If you agree to participate, please sign the informed consent form. After signing, you will be given a copy of this document.

STUDY INFORMATION

Protocol Title:
Prevalence and Natural History of X-linked Dystonia Parkinsonism in Koronadal City, South Cotabato

Principal Investigator: Michael Dorothy Frances Montojo-Tamayo Department of Adult Neurology The Medical City Ortigas Ave., Pasig City, Philippines Tel No. 6356789 loc. 6270

PURPOSE OF THE RESEARCH STUDY

You are being invited to participate in a research study on the Prevalence and Natural History of X-linked Dystonia Parkinsonism in Koronadal City, South Cotabato. XDP is a heredo-degenerative disease endemic to Filipinos particularly those from the island of Panay. You were selected as a possible subject in this study because you have met the inclusion criteria of this study.

STUDY PROCEDURES AND VISIT SCHEDULE

We would like to ask you to consider:
Your consent to the following:  1) thorough standard examination, 2) documentation of clinical history, and 3) data obtained during your clinical examination. These are going to be stored under a pseudonym. Your consent to undergo face-to-face interview.

Schedule of visits and procedures:
The informed consent form will be obtained at the at a clinic in Koronadal City.
After you provide consent, the investigators will obtain baseline demographic information, clinical status, and clinical assessment. They will also conduct a face-to-face interview using standardized tools such as XDP-MDSP. The XDP-MDSP is a rating scale that was formulated to evaluate the severity of your symptoms the effects of these in your day-to-day activities.

All these will be employed on your single visit with us and will take about 30 minutes of your time.

WHO WILL OBTAIN THE INFORMED CONSENT

All investigators will obtain the informed consent.

YOUR RESPONSIBILITIES IN THIS STUDY

If you agree to participate in this study, you should keep your appointments. If it is necessary to miss an appointment, please contact the study staff as soon as you know in order to reschedule another appointment.

WITHDRAWAL FROM STUDY

You are free to withdraw your consent and discontinue your participation at any time without prejudice to you or effect on your medical care. If you decide to stop being part of this study, you should tell the Principal Investigator. On your request, every link between your stored data and your person can be permanently deleted. Your doctor or the Principal Investigator may stop your participation in the study at any time for one or more of the following reasons: Failure to follow the instructions of the Principal Investigator and/or study staff. The Principal Investigator decides that continuing your participation could be harmful. The study is cancelled. Other administrative reasons. Unanticipated circumstances.

POSSIBLE RISKS, DISCOMFORTS AND INCONVENIENCES

There are risks, discomforts and inconveniences associated with any research study. These deserve careful thought. You may experience some discomfort with questions that may be asked.

POTENTIAL BENEFITS

There is no assurance that you will benefit from this study. There will be no monetary reward for participation in this study. However, your participation may contribute to the medical knowledge and improve care for patients with XDP.

SUBJECT'S RIGHTS

Your participation in this study is entirely voluntary.
In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you or your legal representative will be informed in a timely manner by the Principal Investigator or his/her representative.
CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS
Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Only your Investigator(s) will have access to the confidential information being collected.

The Regulatory Agencies, Institution Review Board and Department of Health however, will be granted direct access to your original medical records to check study procedures and data without making any of your information public. By signing the Informed Consent Form attached, you or your legal representative is authorizing such access to your study and local medical records.

Data collected and entered into the Case Report Forms are the property of the researchers. In the event of any publication regarding this study, your identity will remain confidential.

INFORMATION REGARDING DATA PROCESSING, DATA PROTECTION AND DATA SECURITY.
A. An essential safety aspect of the project is the processing of my data in an exclusively pseudonymised manner. What does that mean and how is it carried out?
During your visit, the investigator will enter certain data about you in a data collection form. This form will be assigned a unique code. It will only contain relevant data and will limit any identifying information.

B. Which data do I have to disclose apart from the data required to create my pseudonym in the course of the study?
During the course of the study, some health and/or medical data will be recorded. If you are participating in any subsequent studies, your clinician will give you detailed information about the study and the data required for it accordingly. Each subsequent study requires separate participant consent.

C. Who can see and use my data?
1. You: If you wish so, the investigator can let you see all data stored about you. It is advised that you review these data together with the investigator to explain medical terminologies to you and to answer questions you may have.
2. The investigators conducting the research: The research team are the only ones, apart from yourself, who can access the information gathered for the research.
3. Other groups and individuals: No one, other than the groups and individuals described above, can gain access to or receive the data stored about you.

D. How long are my data stored for?
All data will be stored as entered:
☐ Until you decide to withdraw your participation. Up to a maximum of 10 years after the project activities have stopped.

E. How long will the study be conducted?
This study will be completed in 4 months from initiation. Data collection will start June 2018 until September 2018. September to October 2018 will be dedicated for data analysis and research writing.

COSTS OF PARTICIPATION
If you take part in this study, the following will be performed at no charge to you: Neurologic Examination and XDP-MDSP severity scoring.

RESEARCH RELATED INJURY AND COMPENSATION
The researchers do not make any provisions to compensate subjects for research related injury. However, compensation may be considered on a case-by-case basis for unexpected injuries due to non-negligent causes. In the event that the investigators identify information that is relevant to your care and safety, they will inform your attending physician immediately.

WHO TO CONTACT IF YOU HAVE QUESTIONS
If you have questions about this research study and your rights or in the case of any injuries during the course of this study, you may contact the Principal Investigator.

Principal Investigator:
Michael Dorothy Frances Montojo-Tamayo MD Department of Adult Neurology The Medical City Ortigas Ave., Pasig City, Philippines Tel No. 6356789 loc. 6270
If you have questions about the study or your rights as a participant, you can call The Medical City Institutional Review Board at Tel No: 988-1000 loc.6525 / Fax No. 988-1000 loc.7857 / email: irb@medicalcity.com.ph
Protocol Title:
Prevalence and Natural History of X-linked Dystonia Parkinsonism in Koronadal City, South Cotabato
Principal Investigator: Michael Dorothy Frances Montojo-Tamayo Department of Adult Neurology The Medical City Ortigas Ave., Pasig City, Philippines Tel No. 6356789 loc. 6270
Subject Particulars
Name: ________________________________________________________________________
Address: ________________________________________________________________________
Sex: Female/ Male    Date of Birth: ___________________    dd/mm/yyyy
Part I: To be filled by patient
I, _____________________________________ agree / do not agree to participate in the
(Name of patient) Research study as described and on the terms set out in the
Patient Information Sheet. The nature of my participation in the proposed research study has been explained to me in
by Dr/Mr/Ms ______________________________.
(Dialect/Language)                                           (Investigator)
I have fully discussed and understood the purpose and procedures of this study. I have been given the Patient
Information Sheet and the opportunity to ask questions about this study and have received satisfactory answers and
information. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any
reasons and without my medical care being affected. I also give permission for information in my medical records to be used for research. In any event of publication, I understand that this information will not include my name or other identifiers and that due care will be taken to preserve the confidentiality of this information.

______________________________________                        ________________________
[Signature/Thumbprint (Right / Left) of subject]  (Date of signing)
Part II- to be filled by parents/ legal guardian, where applicable
I, _________________________, hereby give consent for the above patient to participate in the
(proposed research study. The nature, risks, and benefits of the study have been
explained clearly to me and I fully understand them.

_______________________________________________                ______________________
[Signature/Thumbprint (Right / Left) of parent /legal guardian]                 (Date of signing)
Part III- to be filled by witness, where applicable
An impartial witness should be present during the entire informed consent discussion if a subject or the subject's
legally acceptable representative is unable to read. After the written informed consent form and any written
information to be provided to subjects is read and explained to the subject or the subject's legally acceptable
representative, and after the subject or the subject’s legally representative has orally consented to the subject's
participation in the study and, if capable of doing so, has signed and personally dated the consent form, the witness
should sign and personally date the consent form.
Witnessed by:

Signature over Printed Name of witness                  Designation of witness                  Date

Signature over Printed Name of witness
Part IV- Investigator's Statement
I, the undersigned, certify to the best of my knowledge that the patient signing this informed consent form had the
study fully explained and clearly understood the nature, risks and benefits of his/her participation in the study.

______________________________        __________________________ ___________
Name of Investigator
Signature                                   Date

PATIENT INFORMATION SHEET KAG INFORMED CONSENT FORM (HILIGAYNON)
Ginaimbitar ikaw nga makigbahin sa isa ka pagtuon.. Bag-o ka maging kabahin sining pagpanalawsaw kag pagtuon,
kinahanglan nga mapaathag sa imo ang pagtuon kag mahatagan ikaw sang kahigayunan nga makapamangkutanon. Palihog basa sang maayo ang nga impormasyon nga nalakip diri. Kun nagapasugot ikaw nga makigbahin, palihog
pirma sang informed consent form. Hatagan ikaw sang kopya nga mahimo mo madala pauli.

IMPOMASYON SANG PAGTUON
Tigulo sang Protocol:
Prevalence and Natural History of X-linked Dystonia Parkinsonism in Koronadal City, South Cotabato
Puno nga Tigpanalawsaw:
Principal Investigator: Michael Dorothy Frances Montojo-Tamayo Department of Adult Neurology The Medical City Ortigas Ave., Pasig City, Philippines Tel No. 6356789 loc. 6270
TINUTUYO SANG PAGTUON

Ginaagda ikaw nga makigbahin sa isa ka paganalawsaw kag pagtuon sa Prevalence and Natural History of X-linked Dystonia Parkinsonism in Koronadal City, South Cotabato. Ang XDP isa ka heredo-degenerative nga sakit nga masami para sa mga Filipino, particular sa mga yara sa isla sang Panay.. Napiliwan ikaw nga manging tagpumasakop sa pagtuon nga ini bangud may yara ikaw sang X-linked Dystonia-Parkinsonism (XDP) kag nagasibo man sa iwan nga mga panuntunan nga malakip sa sini nga pagtuon.

PROSESO SANG PAGTUON KAG SKEDYUL SANG PAGBISITA

Luyag namon nga binagbinagon mo ang mga masunod:

1) ang pagpasugot mo sa isa ka matul-id nga pag eksamin kag paglista sang impormasyon lakip na ang imo clinical history kag datos nga makuhana sa imo examination nga pagataguon sa idalom sang isa ka alyas. Ang imo pagpasugot sa isa ka interbyu.

Skedyul sang pagbisita kag proseso:

Isa ka Pagbisita: Ang informed consent form pagakuhaon sa klinika sa Koronadal City.

Matapos mo maghatag sang pagpasugot, ang mga tigpanalawsaw magakuha sang baseline demographic information, clinical status, kag clinical assessment. Magapatigayun man sila sang pagistorya sa imo kag paginterbyu gamit ang XDP-MDSP.

Ang XDP-MDSP isa ka validated rating scale nga gindisenyo para taksun ang kagrabihon sang dystonic, parkinsonian, kag non-motor nga symptomas sang pasyente nga may XDP kag ang epekto sini sa matag-adlaw nga pagpangabuhi sang pasyente.

Ini tanan pagagamiton sa imo kaisa nga pagkabulag sang mga 30 minutas lamang sang imo oras.

SIN-O ANG MAGAKUHA SANG INFORMED CONSENT

Tanan nga tigpanalawsaw magakuha sang informed consent.

ANG IMO RESPONSIBILIDAD SA SINI NGA PAGTUON

Kung nagagpasugot ka makigbahin sa sini nga pagtuon kinahanglan mo nga: □ Kadtuon ang imo study appointment.

Kun indi ikaw makakadto, makig-angot sa katapo sang pagtuon agud mapailisan sang iban nga petsa ang imo skedyul sa pinakatimprano nga ka gihayagun nga mabal-an mo nga indi ikaw makakadto sa natalana nga adlaw.

PAGBAWI HALIN SA PAGTUON

Libre ikaw nga magbawi sang imo pagpasugot kag indi na magpadayun sa pagpakigbahin sa pagtuon sa anong nga tinion nga imo gustuhon kag indi ini makaapekto sa imo ginabatun nga medikal nga pagtatag kag pagbulong. Kun pillion mo nga indi na magpakikibirin sa sini nga pagtuon, kinahanglan mo pabal-on ang Puno nga Tiganalawsaw. Sa imo man pagpamagabay, tanan nga natago nga mga datos kag impormasyon kag ang imo kaangtanan sa mga ini pagpanason sang gilayon.. Ang imo duktor, ang Puno nga Tiganalawsaw mahimo man magdesisyon nga untaton ang imo pagkigbahin sa pagtuon sa anong nga tinion nga imo masunod nga mga rason: Indi pagsunod sa mga panuntunan sang Puno nga Tiganalawsaw kag/o mga katapo sang pagtuon. Ang pagdesisyong sang Puno nga Tiganalawsaw nga ang padayun mo nga pagkigbahin sa pagtuon makahalit sa imo. Pagaparamat sa pagtuon. Iban pa nga mga administratibo nga mga rason. Wala ginalaunan nga mga sirkumstansya.

POSIBLE NGA MGA RISGO, INDI PAGKAKOMPORTABLE KAG MGA SABLAG

May mga risgo, indi pagkakomportable kag mga sablag nga naangot sa pagtuon. Kinahanglan sila paminsaran sing maayo. Mahimo ka makabatyag sang indi pagkakumportable sa mga pamangkutan nga pwede ipamangkot sa imo.

MAHIMO NGA MGA MABENEPISYO

Wala sang kasiguruan nga mga magabepisyo ka sa sini nga pagtuon. Wala sang kwarta na ihatag sa imo sa pag ambit ini nga pagtuon. Apan ang imo pagpakigbahin mahimo nga makaamot sa kinaadman medikal kag kun paano pa mas mapayaan kag mapasanyag ang patagtap sa mga pasyente nga may XDP.

KINAMATARONG SANG PASYENTE

Ang pagkigbahin mo sa sini nga pagtuon, puro nga boluntaryo lamang. Ang mga pamangkutanon mo pagasabton sang klaro kag sa imo ikaintindi.

Sa oras nga may bag o nga impormasyon nga may kaangtanan sa imo nga pagpasugot sa pagpadayun sa sini nga pagtuon, ikaw o ang imo legal nga tiglawa pagpabal-on gilayon sang Puno nga Tiganalawsawo sang iya tiglawa. PAGKAKUMPIDENSYAL SANG PAGTUON KAG MGA REKORD MEDIKAL

Ang mga impormasyon nga matipon sa sini nga pagtuon pagataguon sa istrikto nga pagkakumpidensyal. Ang imo nga mga rekords, sa sakop sang mga layi kag regulasyon, indi pagisasapliko. Ang imo lang tiganalawsaw ang may uyat sang mga kompidensyal nga mga impormasyon nga matipon.

Ang mga Regulatory Agencies, Institution Review Board kag Department of Health ugaling, hatagan sang direkta nga akses sa imo orihinal nga medical records agud masikyar ang proseso sang pagtuon kag ang mga datos nga indi
nagakinahanglan sang pagsapubliko sang mga ini. Sa pagpirmma mo Informed Consent Form nga nalakip, ikaw o ang imo legal nga tiglawas nagahatag pagpasugot sa akses sa imo datos sa pagtuvo kaag sa imo lokal nga mga medical records.

Ang mga datos nga natapon kaag napasulod sa Case Report Forms ginapanag-iyahan sang mga tigpanalawsaw. Sa oras nga may pagimprinta o pagbalhag sang sini nga pagtuvo, ang imo pagkakilalan magapabilin nga nahanago kag kumpedensyal.

IMPORMASYON TUHOY SA PAGPROSESO SANG DATOS, PAGTIPIG SA MGA DATOS KAG SEGURIDAD SANG MGA DATOS.

A. Isa sa mga importante nga aspeto sa seguridad sang proyekto amo ang pagproseso sa mga datos sa pamaagi sing bug-os nga paghatag alyas. Ano ang buot silingon sini kag paano ini ginapatiguyun?

Sa imo pagbisita, ang mga tigpanalawsaw magapasulod sang pila ka mga datos nahanungod sa imo sa isa ka collection form. Ini nga pormas pagahatahan sing numero nga nakacode. May mga kaangot lamang ini nga mga datos kag limitado ang mga impormasyon nga magahatag pagkakilalan sa imo.

B. Ano pa gid nga mga datos ang kinhahanglan ko ihatag magluwas sa mga datos nga ginakinahanglan sa pagbuhat sang akon alyas para sa pagtuvo?

Sa bilog nga pagtuvo, pila ka mga health kag/o medical data ang pagalistahon. Kun magapasakop ka sa masunod nga mga datos nga natapon nga datos nga natago nahanungod nga mga datos nga kau sa mga datos nga natapos nga pagsugot. Sa kada pagtuvo, ginakinahanglan ang luwas nga pagpasugot.

C. Sin-o ang makakita kag makagamit nga akon mga datos?

1. Ikaw: Kun luyag mo, ang tigpanalawsaw mahimo nga makapakita sa imo nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natago nga datos nga natag
Tigulo sang Protocol:
Prevalence and Natural History of X-linked Dystonia Parkinsonism in Koronadal City, South Cotabato
Puno nga Tigpanalawsaw:
Michael Dorothy Frances Montojo-Tamayo Department of Adult Neurology The Medical City Ortigas Ave., Pasig City, Philippines Tel No. 6356789 loc. 6270

Impormasyon sang Pasyente
Ngalan: _________________________________________________________
Address: ________________________________________________________________________
Sex: Female/ Male    Date of Birth: ___________________   dd/mm/yyyy

Part I: Pagasabtan sang pasyente
Ako si, _____________________________________ nagapa sugot / wala nagapasugot
(Ngalan sang pasyente)                              nga makigbahin sa participate in the pagpanalawsaw kag pagtuon nga ginpaathag sa ibabaw sa Patient Information Sheet. Ang akon pagpasakop sa ginapatigayon nga pagtuon kag pagpanalawsaw napaathag sa akon sang kumpleto, klaro kag detalyado, sa ______________________ ni Dr/Mr/Ms ______________________________.
(Pulong /Lengwahe/ Dialekto)                       (Ngala n sang tigtatap medikal)
Napaathag sa akon kag naghinununan-anon, kag lubos ko nga naintindihan ang tinutuyo kag ang proseso sang sini nga pagtuon. Nahatagan ako sang Patient Information Sheet kag nahatagan man ako sang kabigayunan nga mappamangkot nahunungod sa sining pagtuon kag nasabat sing klaro, maathag kag bug-os ang akon mga pamangkot kag nahatagan ako sing nagakig nga impormasyon.
Naintindihan ko nga ang akon pakigbahin boluntaryo kag hilway ako sa pagbawi sa bisan ano nga tinion sang akon pagpasugot nga wala nagakinahanglan maghatag sang anong man nga rason, kag wala ini sang epekto sa akon ginabaton nga pagtatap medikal.
Ginahatag ko man ang akon permiso kag pagpasugot sa akon nga impormasyon kay ang akon medical records magamit sa sini nga pagtuon. Sa tiona sang pagpaimprenta o pagbalhag, naintindihan ko nga ang impormasyon nga ini indi magalakip sang akon ngalan o iban ano nga tinion sang akon pagpasagot nga wala nagakinahanglan maghatag sang anong man nga rason, kag wala ini sang epekto sa akon ginabaton nga pagtatap medikal.

______________________________________                        ______________________
[Pirma/Thumbprint (Tuo/ Wala) sang pasyente]                            (Petsa sang pagpirma)

Part II- sabtan sang ginikanan o legal nga tiglawas kun kinahanglanon
Ako si, _________________________, nahingadlan sa ibabaw nga magpasakop sa ginapatigayon nga pagpanalawsaw/pagtuon. Ang pagtuon, mga risgo kag benepisyo sang pagtuon napaathag na sang klaro sa akon kayak naintindihan ko ini sing lubos.

_______________________________________________                           ______________________
[Pirma/Thumbprint (Tuo/ Wala) sang ginikanan o legal nga tiglawas]          (Petsa sang pagpirma)

Part III- sabtan sang saksi kun kinahanglanon
May patas nga saksi nga dapat yara samtang ginadiskusyon kag ginapaathag ang informed consent kun ang pasyente o ang legal nga tiglawas sang pasyente indi makahibalo magbasa. Matapos basahon ang nakasulat nga informed consent kag ipabawe nga mga makapamagot nga impormasyon nga dapat igapabalo kag igapahatag sa pasyente o sa legal nga tiglawas sang pasyente, kag matapos ang pasyente o ang legal nga tiglawas sang pasyente nakabutyag sang pagpasagot sa pagtuon, kag kun masarangan, makapirma mag mapetsahan ang consent form, ang saksi magapirma man kay petsahan ang consent form.

Ginsaksihan ni:

______________________________________     ______________________
[Pirma/Thumbprint (Tuo/ Wala) sang ginikanan o legal nga tiglawas]          (Petsa sang pagpirma)

Part IV- Pagpahayag sang Tigpanalawsaw
Ako, nga nakapirma sa idalom nagapamatuod nga sa pinakamaayo sang akon nahibal-an nga ining pasyente nga nagapirma sang informed consent form napaathagangan nga nahanungod sa pagtuon kag naintindihan ang pagtuon, risgo kag benepisyo sang iya pagpasakop sa sini nga pagtuon.

______________________________________     ______________________
Ngalan Sang Tigpanalawsaw                                    Pirma                              Petsa

______________________________________     ______________________
Pirma sa ibabaw sang ngalan                                    Designasyon sang saksi                  Petsa

______________________________________     ______________________
Pirma sa ibabaw sang ngalan                                    Designasyon sang saksi                  Petsa

______________________________________     ______________________
Pirma sa ibabaw sang ngalan                                    Designasyon sang saksi                  Petsa

______________________________________     ______________________
Part IV- Pagpahayag sang Tigpanalawsaw                           Designasyon sang saksi                  Petsa

Part IV- Pagpahayag sang Tigpanalawsaw
Ako, nga nakapirma sa idalom nagapamatuod nga sa pinakamaayo sang akon nahibal-an nga ining pasyente nga nagapirma sang informed consent form napaathagangan nga nahanungod sa pagtuon kag naintindihan ang pagtuon, risgo kag benepisyo sang iya pagpasakop sa sini nga pagtuon.

______________________________________     ______________________
Pirma sa ibabaw sang ngalan                                    Designasyon sang saksi                  Petsa

6
APPENDIX 1C
DATA COLLECTION FORM

A. DEMOGRAPHICS
PATIENT NAME: 
AGE: 
SEX: 
ADDRESS: 
CONTACT NUMBER: 

B. FAMILY PROFILE
Is there a positive family history?
If yes, how are they related to the patient?
______________________________________________________________
______________________________________________________________
Are there deaths due to XDP? How many?
______________________________________________________________
Place of origin of mother:________________________________________

C. CLINICAL FEATURES
Age of onset:_____________________________________________________________
Duration of Illness:_____________________________________________________________
Initial presentation: _____ Dystonia _____ Parkinsonism
Current presentation: _____ Dystonia _____ Parkinsonism
Initial area of involvement:
____Craniofacial _____ Cervical and shoulder _____ Trunk _____ Upper extremities _____ Lower Extremities
If with dystonia:
Current presentation: _____ Focal _____ Segmental _____ Multifocal _____ Generalized _____ Parkinsonism
If this patient has generalized dystonia, how many years from onset did it generalize? _______
If this patient has Parkinsonism, how many years from onset did it develop? _______
APPENDIX 1D

Questionnaires/ Data collection forms

XDP RATING SCALE

XDP-MDSP RATING SCALE

<table>
<thead>
<tr>
<th>Patient ID:</th>
<th>Site:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
<td>Examiner:</td>
</tr>
</tbody>
</table>

Time of last medication intake: ________
Duration of Illness: _____________

PART I: DYSTONIA

1. EYES AND UPPER FACE

Specific Instructions: Ask the patient (or caregiver) how often, in the past week, s/he has noticed increased blinking, forceful eye closure, or forehead wrinkling. Then ask the patient to tightly open and close eyes five times

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Increased blinking or slight forehead wrinkling/ lid retraction AND dystonia over eyes and/or upper face occurring less than 26% of the time during waking hours in the past week
2 = Mild OR Often: Increased blinking with some eye closure but without squeezing/ mild forehead wrinkling OR dystonia over eyes and/or upper face occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Eye closure with squeezing but still within 10 seconds able to open eyes within 10 seconds/ with pronounced forehead wrinkling OR dystonia over eyes and/or upper face occurring 51-75% of the time during waking hours in the past week
4 = Severe: OR All the time: Eyes closed most of the time/ eye closure with squeezing, unable to open eyes within 10 seconds/ persistent forehead wrinkling with pronounced forehead lines OR dystonia over eyes and/or upper face occurring more than 75% of the time during waking hours in the past week

2. JAW, TONGUE AND LOWER FACE

Specific Instructions: Ask the patient (or caregiver) how often, in the past week, has s/he noted involuntary grimacing of the lower face, jaw or tongue protrusion/retraction. Then ask the patient to open and close the jaw five times; ask the patient to protrude, retract and move tongue side to side

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight grimacing of lower face, easily able to relax/ slight jaw protrusion or retraction/ slight tongue protrusion or retraction AND dystonia over the jaw, tongue or lower face occurring less than 26% of the time during waking hours in the past week
2 = Mild OR Often: Mild grimacing of the lower face with minimal distortion of the mouth/ mild jaw protrusion or retraction, with some difficulty relaxing/ mild tongue protrusion or retraction or rolling OR dystonia over jaw, tongue or lower face occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Grimacing of lower face with moderate distortion of the mouth/ moderate jaw protrusion or retraction/ spontaneous tongue protrusion beyond the lips/ difficulty retracting tongue to normal position/ cheek pushed due to tongue rolling OR dystonia over jaw, tongue or lower face occurring 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Persistent grimacing of the lower face/ unable to relax jaw/ jaw dislocated/ unable retract or protrude tongue / tongue fully protruded OR dystonia over jaw, tongue or lower face occurring more than 75% of the time during waking hours in the past week

3. LARYNX

Specific Instructions: Ask the patient (or caregiver), how often, over the past week, has s/he noticed having hoarseness, choked voice or voice breaks when talking. Converse with the patient, then ask to vocalize “eeeee” for 5 seconds

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Barely detectable hoarseness/ choked voice or voice breaks AND occurring less than 26% of the time
2 = Mild OR Often: Obvious hoarseness/ frequent voice breaks and choked voice OR occurring 26 – 50% of the time
3 = Moderate OR Frequent: Marked hoarseness/ choked voice or continuous voice breaks OR occurring 51-75% of the time
4 = Severe OR All the time: Unable to vocalize / presence of audible respiratory grunts or wheezing / presence of tridor OR occurring more than 75% of the time

4. NECK AND SHOULDER (elevation, anterior and posterior displacement)
Specific Instructions: Ask the patient (or caregiver) how often, over the past week, has s/he noticed involuntary neck deviation or shoulder elevation. Then ask the patient to walk at least 5 meters and observe neck rotation, flexion, extension and shoulder elevation, anterior and posterior displacement

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight deviation of the neck and shoulder that occurs only with maneuvers AND occurring dystonia over neck and/or shoulders occurring less than 26% of the time during waking hours in the past week
2 = Mild OR Often: Mild deviation of the neck and shoulder even without maneuvers OR dystonia over neck and/or shoulders occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Significant deviation of the neck and shoulder but still able to relax OR dystonia over neck and/or shoulders occurring less than 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Fixed deviation of the neck and shoulder with inability to relax OR dystonia over neck and/or shoulders occurring more than 75% of the time during waking hours in the past week

5. UPPER AND LOWER TRUNK

Specific Instructions: Ask the patient (or caregiver) how often, over the past week, has s/he noticed involuntary rotation, deviation, flexion or extension of the trunk. Then observe the patient while lying down, seated, standing, and walking for at least 5 meters. Observe for rotation, lateral deviation, flexion or extension.

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight deviation of the trunk that occurs only when walking AND dystonia over the trunk occurring less than 26% of the time during waking hours in the past week
2 = Mild OR Often: Mild deviation of the trunk seen while lying down, seated or standing OR dystonia over the trunk occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Significant deviation of the trunk but still able to ambulate without assistance OR dystonia over the trunk occurring less than 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Persistent deviation of the trunk and able to stand and ambulate only with assistance/ unable to maintain sitting position OR dystonia over the trunk occurring more than 75% of the time during waking hours in the past week

6A. RIGHT UPPER EXTREMITY

Specific Instructions: Ask the patient (or caregiver) how often, over the past week, has s/he noticed involuntary posturing of the right upper extremity. Then observe the patient with hands on the lap and ask the patient to fully extend the arms. Then with arms outstretched in front, ask the patient to fully pronate and supinate for five times

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight posturing and seen only with maneuvers AND dystonia of the extremity occurring less than 25% of the time during waking hours in the past week
2 = Mild OR Often: Mild posturing and seen even without maneuvers OR dystonia of the extremity occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Significant posturing is present with difficulty performing maneuvers OR dystonia of the extremity occurring less than 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Fixed posturing and unable to perform maneuvers OR dystonia of the extremity occurring more than 75% of the time during waking hours in the past week

6B. LEFT UPPER EXTREMITY

Specific Instructions: Ask the patient (or caregiver) how often, over the past week, has s/he noticed involuntary posturing of the left upper extremity. Then observe the patient with hands on the lap and ask the patient to fully extend the arms. Then with arms outstretched in front, ask the patient to fully pronate and supinate for five times

0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight posturing and seen only with maneuvers AND dystonia of the extremity occurring less than 26% of the time during waking hours in the past week
2 = Mild OR Often: Mild posturing and seen even without maneuvers OR dystonia of the extremity occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Significant posturing is present with difficulty performing maneuvers OR dystonia of the extremity occurring less than 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Fixed posturing and unable to perform maneuvers OR dystonia of the extremity occurring more than 75% of the time during waking hours in the past week

7A. RIGHT LOWER EXTREMITY

Specific Instructions: Ask the patient (or caregiver) how often, over the past week, has s/he noticed involuntary posturing of the right lower extremity. Ideally, without footwear, observe the patient’s lower extremities with legs dangling then with feet flat on the floor. Ask the patient to walk for at least 5 meters. Observe for any deviations.
0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight posturing and seen only when walking AND dystonia of the extremity occurring less than 25% of the time during waking hours in the past week
2 = Mild OR Often: Mild posturing and seen even without walking OR dystonia of the extremity occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Significant posturing is present with difficulty walking OR dystonia of the extremity occurring less than 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Fixed posturing and able to ambulate only with assistance OR dystonia of the extremity occurring more than 75% of the time during waking hours in the past week

7B. LEFT LOWER EXTREMITY
Specific Instructions: Ask the patient (or caregiver) how often, over the past week, s/he has noticed involuntary posturing of the left lower extremity. Ideally, without footwear, observe the patient’s lower extremities with legs dangling then with feet flat on the floor. Ask the patient to walk for at least 5 meters. Observe for any deviations.
0 = Normal AND None: Absent signs and symptoms
1 = Slight AND Seldom: Slight posturing and seen only when walking AND dystonia of the extremity occurring less than 25% of the time during waking hours in the past week
2 = Mild OR Often: Mild posturing and seen even without walking OR dystonia of the extremity occurring 26-50% of the time during waking hours in the past week
3 = Moderate OR Frequent: Significant posturing is present with difficulty walking OR dystonia of the extremity occurring less than 51-75% of the time during waking hours in the past week
4 = Severe OR All the time: Fixed posturing and able to ambulate only with assistance OR dystonia of the extremity occurring more than 75% of the time during waking hours in the past week

8. POSTURE AND BALANCE
Specific Instruction: Ask the patient to stand erect then ask the patient to stand on one foot for five seconds. Repeat with the other foot. Score the worse side.
0 = Normal: Able to stand erect and stand on one foot
1 = Slight: Able to stand erect with slight difficulty standing on one foot but still able to do so for 5 seconds
2 = Mild: Able to stand erect but able to stand on one foot for less than 5 seconds only
3 = Moderate: Some difficulty standing erect or unable to stand on one foot
4 = Severe: Unable to stand on both feet

9. GAIT AND AMBULATION
Specific Instructions: Ask the patient to walk for five meters. Observe how the dystonia affects the gait
0 = Normal: Normal gait
1 = Slight: Gait is affected but can walk independently
2 = Mild: Ambulates with difficulty and may require some assistance
3 = Moderate: Can ambulate only with assistance
4 = Severe: Can no longer ambulate even with assistance
Total Subscale Score: _______

PART II: PARKINSONISM
There are 8 items to be scored. For some items, different body parts or the left and right side may need to be scored separately. Rate the maximal severity of parkinsonism at the time of examination. Specifically for tremors, if maximal severity appears in a body part after you have scored that item, you may go back to re-score.

SPEECH
Specific Instructions: Ask the patient what s/he had for breakfast today or dinner last night. Ask the patient to recite the months of the year in his/her normal speaking voice.
0 = Normal: Absent signs and symptoms
1 = Slight: Slight decrease in volume or slightly slower speech
2 = Mild: Clear monotony in the voice but speech is not slurred
3 = Moderate: Slurred speech but still generally understandable
4 = Severe: Unintelligible speech

RESTING TREMORS
Specific Instructions: Instruct the patient to put his/ her feet flat on the floor, place his/ her hands on the lap and recite the months of the year starting from December going backwards. Do this on both upper and lower extremities. Be careful in classifying tremors. Parkinsonian tremors are usually rhythmic to-and-fro movements of a
body part, typically worse in the resting position. Rate the maximal resting tremor observed. Dystonic tremors, however, are typically irregular in rhythm and vary in amplitude, usually in the setting of an abnormal posturing of the shaking body part. Do not rate these.

A. Face, Lips and Chin:
0 = Normal: Absent signs and symptoms
1 = Slight: Tremors are of very low amplitude and present only with reinforcement
2 = Mild: Tremors are of mild amplitude and persistent OR moderate amplitude but intermittent
3 = Moderate: Tremors are of moderate amplitude and present most of the time
4 = Severe: Tremors are of marked amplitude and present most or all the time

B. Upper Extremities:
0 = Normal: Absent signs and symptoms
1 = Slight: Tremors are of very low amplitude and present only with reinforcement
2 = Mild: Tremors are of mild amplitude and persistent OR moderate amplitude but intermittent
3 = Moderate: Tremors are of moderate amplitude and present most of the time
4 = Severe: Tremors are of marked amplitude and present most or all the time

C. Lower Extremities
0 = Normal: Absent signs and symptoms
1 = Slight: Tremors are of very low amplitude and present only with reinforcement
2 = Mild: Tremors are of mild amplitude and persistent OR moderate amplitude but intermittent
3 = Moderate: Tremors are of moderate amplitude and present most of the time
4 = Severe: Tremors are of marked amplitude and present most or all the time

RIGIDITY
Specific Instructions: Ask the patient to relax as much as possible. Slowly test the range of motion and tone of each body part. Start with the extremities and end with the neck region. With each maneuver, if the tone is normal and with full range of motion, ask the patient to open and close the contralateral hand. Do this on both upper and lower extremities and the neck. Rate the maximum rigidity observed within the body region.

A. Upper Extremities
0 = Normal: Absent signs and symptoms
1 = Slight: Increased tone detected only with activation procedures
2 = Mild: Mild rigidity appreciated even without activation procedures
3 = Moderate: Moderate rigidity, full range of motion achieved with some difficulty
4 = Severe: Full range of motion can barely be achieved

B. Lower Extremities
0 = Normal: Absent signs and symptoms
1 = Slight: Increased tone detected only with activation procedures
2 = Mild: Mild rigidity appreciated even without activation procedures
3 = Moderate: Moderate rigidity, full range of motion achieved with some difficulty
4 = Severe: Full range of motion can barely be achieved

C. Neck
0 = Normal: Absent signs and symptoms
1 = Slight: Increased tone detected only with activation procedures
2 = Mild: Mild rigidity appreciated even without activation procedures
3 = Moderate: Moderate rigidity, full range of motion achieved with some difficulty
4 = Severe: Full range of motion can barely be achieved

FINGER TAPS
Specific Instructions: Ask the patient to tap thumb with the index finger in rapid succession 10 times as fast and as wide as possible; demonstrate then ask the patient to do the maneuver on his/her own.

A. Right
0 = Normal: Absent signs and symptoms
1 = Slight: Slight slowing and/or reduction in amplitude is noted
2 = Mild: Mild but clear slowing observed and/or occasional arrests in movements
3 = Moderate: Moderate slowness with frequent hesitation/arrests
4 = Severe: Can barely perform the task

B. Left
0 = Normal: Absent signs and symptoms
1 = Slight: Slight slowing and/or reduction in amplitude is noted
2 = Mild: Mild but clear slowing observed and/or occasional arrests in movements
3 = Moderate: Moderate slowness with frequent hesitation/ arrests
4 = Severe: Can barely perform the task

ALTERNATING HAND MOVEMENTS
Specific Instructions: Ask the patient to do alternating pronation and supination motions of the hands in rapid succession 10 times, one hand at a time, as full and as fast as possible. Demonstrate then ask the patient to do the maneuver on his/her own.

A. Right
0 = Normal: Absent signs and symptoms
1 = Slight: Slight slowing and/or reduction in amplitude is noted
2 = Mild: Mild but clear slowing observed and/or occasional arrests in movements
3 = Moderate: Moderate slowness with frequent hesitation/ arrests
4 = Severe: Can barely perform the task

B. Left
0 = Normal: Absent signs and symptoms
1 = Slight: Slight slowing and/or reduction in amplitude is noted
2 = Mild: Mild but clear slowing observed and/or occasional arrests in movements
3 = Moderate: Moderate slowness with frequent hesitation/ arrests
4 = Severe: Can barely perform the task

LEG AGILITY
Specific Instructions: Ask the patient to tap his heel on the ground in rapid succession 10 times as high and as fast as possible, lifting up the entire leg. Do this one side at a time; demonstrate it, then ask the patient to do this on his/her own.

A. Right
0 = Normal: Absent signs and symptoms
1 = Slight: Slight slowing and/or reduction in amplitude is noted
2 = Mild: Mild but clear slowing observed and/or occasional arrests in movements
3 = Moderate: Moderate slowness with frequent hesitation/arrests
4 = Severe: Can barely perform the task

B. Left
0 = Normal: Absent signs and symptoms
1 = Slight: Slight slowing and/or reduction in amplitude is noted
2 = Mild: Mild but clear slowing observed and/or occasional arrests in movements
3 = Moderate: Moderate slowness with frequent hesitation/arrests
4 = Severe: Can barely perform the task

ARISING FROM THE CHAIR
Specific Instructions: While seated, ask patient to fold his arms across his/her chest and attempt to quickly stand up.

0 = Normal: Absent signs and symptoms
1 = Slight: Slow in standing, or may need more than 1 attempt but can do so without using the arm rest of the chair
2 = Mild: Needs to push self from the arm rest of the chair
3 = Moderate: Needs more than 1 attempt despite using the arm rest of the chair but still able to do so without help
4 = Severe: Unable to arise without help

GAIT FREEZING AND SHUFFLING
Specific Instructions: Ask the patient to walk 5 meters and turn a couple of times. Observe for shuffling, freezing and hesitation.

0 = Normal: No shuffling, freezing or hesitation
1 = Slight: Rare difficulty in walking, shuffling or hesitation is noted, but generally steady and confident gait
2 = Mild: Mild difficulty in walking, some short festination or hesitation, or turns en bloc but still able to walk without assistance
3 = Moderate: Moderate difficulty in walking requiring a walking aid (eg. cane, walker, etc.) but still able to do so independently
4 = Severe: Wheel chair- or bed-bound unless aided

Total Subscale Score: _______

PART III: NON-MOTOR FEATURES
This subscale is divided into two parts. Part IIIA (BEHAVIORAL segment) is Clinician-administered, and Part IIIB (NON-BEHAVIORAL segment) is Patient- or Caregiver-administered.
Part IIIA (Behavioral Segment, Clinician-Administered)
There are 5 items to be scored

Primary source of information (circle one):
PATIENT     CAREGIVER     BOTH (IN EQUAL PORTION)

COGNITION
Instruction to Examiner: Consider all types of altered level of cognitive function, including cognitive slowing, impaired reasoning, memory loss, deficits in attention and orientation. Then, rate their duration and interference with patient’s ability to carry out daily routines and engage in social interactions.
To be read to patients (and caregivers): “Over the past week, have you had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town? How much do these problems with memory and concentration bother you or affect your day-to-day activities?” [If yes, examiner asks patient or caregiver to elaborate and probes for information]
0 = Normal: No signs/symptoms of cognitive impairment for the past week
1 = Slight: Cognitive impairment recognized by patient and/or caregiver but creates no interference in the patient’s ability to carry out daily routines and engage in social interactions
2 = Mild: Cognitive impairment occasionally interferes but does not prevent the patient’s ability to carry out daily routines and engage in social interactions
3 = Moderate: Cognitive impairment significantly interferes, but does not totally prevent the patient’s ability to carry out daily routines and engage in social interactions
4 = Severe: Cognitive impairment totally prevents the patient’s ability to carry out daily routines and engage in social interactions

APATHY
Instruction to Examiner: Consider level of spontaneous activity, assertiveness, motivation and initiative, and rate its and interference with patient’s ability to carry out daily routines and engage in social interactions. In this category, the examiner should attempt to distinguish between apathy and similar symptoms that are best explained by depression.
To be read to patients (and caregivers): “Over the past week, did you have difficulty starting/initiating or have you lost interest in doing your usual or recreational activities? Have you lost interest in interacting and socializing with people? How much has your difficulty initiating or lack of interest affected your day-to-day activities and social interactions?” [If yes, Examiner asks patient or caregiver to elaborate and probes for information]
0 = Normal: No signs/symptoms of apathy over the past week
1 = Slight: Apathy recognized by patient and/or caregiver but creates no interference in the patient’s ability to carry out daily routines and engage in social interactions
2 = Mild: Apathy occasionally interferes but does not prevent the patient’s ability to carry out daily routines and engage in social interactions
3 = Moderate: Apathy significantly interferes, but does not totally prevent the patient’s ability to carry out daily routines and engage in social interactions
4 = Severe: Apathy prevents the patient’s ability to carry out daily routines and engage in social interactions

ANXIETY
Instruction to Examiner: Determine nervous, tense, worried or anxious feelings (including panic attacks) over the past week and rate their duration and interference with patient’s ability to carry out daily routines and engage in social interactions.
To be read to the patient (and caregiver): “Over the past week, have you felt nervous, anxious, or uneasy? Did you experience palpitations, shortness of breath, and other physical symptoms in association with your nervousness? How has this affected your day-to-day activities and your social interactions?”
0 = Normal: no signs/symptoms of anxious feelings over the past week
1 = Slight: Slight or intermittent anxiety feelings that does not cause interference in the patient’s ability to carry out daily routines and engage in social interactions
2 = Mild: Clear anxiety feelings that occasionally interfere but do not prevent the patient’s ability to carry out daily routines and engage in social interactions
3 = Moderate: Significant anxiety that frequently interferes, but do not totally prevent the patient’s ability to carry out daily routines and engage in social interactions
4 = Severe: Severe and persistent anxiety feelings that prevent the patient’s ability to carry out daily routines and engage in social interactions

DEPRESSION
Instruction to Examiner: Consider low mood, sadness, hopelessness, guilt, feelings of emptiness, or loss of enjoyment. If the patient is SUICIDAL (whether planned, attempted or failed), Category 4 [severe] should be automatically chosen.

To be read to the patient (and caregiver): “Over the past week, did you feel sad, ‘blue’, or hopeless? Did you feel guilty sometimes that you have not lived up to expectations or you are causing undue burden to others? Did you sometimes wish that life as not worth living? Did you ever act on these thoughts?”

0 = Normal: No signs/symptoms of depressed mood over the past week)
1 = Slight: Slightly and transiently depressed mood does not cause interference in the patient’s ability to carry out daily routines and engage in social interactions
2 = Mild: Mildly depressed mood occasionally interferes but does not prevent the patient’s ability to carry out daily routines and engage in social interactions
3 = Moderate: Significantly depressed mood most of the time that frequently interferes, but does not totally prevent the patient’s ability to carry out daily routines and engage in social interactions
4 = Severe: Severe and persistent depressed mood that prevents the patient’s ability to carry out daily routines and engage in social interactions

IRRITABILITY AND AGGRESSION

Instruction to Examiner: Consider the patient’s dealing with caregiver and other people around. This includes lack of impulse control, unpleasant, irritable, and aggressive behaviors. Then rate their duration and interference with patient’s ability to carry out daily routines and engage in social interactions.

To be read to the patient (and caregiver): “Over the past week, have you felt angry or irritable? Did you feel you were ‘short fused’ and easily upset and irritated over minor things? Did you constantly argue or yell or hit people around you? Did you have difficulty controlling your emotions or desires?

0: Normal: No signs/symptoms of unpleasant behavior for the past week
1 = Slight: Slight and occasional unpleasant behavior but does not cause interference in the patient’s ability to engage in social interactions
2 = Mild: Mild unpleasant behavior that has somewhat affects the patient’s ability to engage in social interactions
3 = Moderate: Unpleasant behavior that significantly affects the patient’s ability to engage in social interactions
4 = Severe: Severe and persistent unpleasant behavior with physical aggressiveness and/or verbal abusiveness that prevents any meaningful social interaction

Total subscale score: _______

Part IIIB (Non-Behavioral Segment; Patient/Caregiver-Administered)

There are 5 items to be scored.

Patient (or Caregiver) Instructions: Sometimes, people with your condition, experience certain symptoms such as pain, fatigue, and problems with sleep and urination. We would like to ask you questions about these symptoms. Please choose the best response that describes how you have felt ON AVERAGE during the PAST WEEK including today. It is possible that some of these questions will not apply to you now or ever, so please do not worry as you respond to these questions. If you are not experiencing these problems, you can simply respond NO to the questions.

Who answered this form today? (circle one):
PATIENT
CAREGIVER

If caregiver: What is your relationship to the patient? _____________________

SLEEP DISTURBANCE

Over the past week, how would you rate your ability to fall asleep at night, and your ability to stay asleep? Did you wake up in the morning feeling rested? Did you have to take sleeping pills to help you sleep or stay asleep?

0 = I have no sleep problems in the past week and I feel rested when I wake up.
1 = I had a slight problem sleeping in 1 or 2 nights only in the past week.
2 = I had difficulty sleeping about half the nights in the past week.
3 = I had difficulty sleeping most of the nights in the past week and I don’t feel rested when I woke up. Sometimes, I have to take sleeping pills to fall asleep.
4 = I am unable to sleep without my sleeping pills.

PAIN AND OTHER SENSATIONS

Over the past week, have you had uncomfortable feelings in your body such as pain, aches, tingling or cramps?

How bothersome were they? Did it prevent you from doing your day-to-day activities or interfere with your sleep?

0 = I had no uncomfortable feelings/pain in the past week.
1 = I experienced mild and transient uncomfortable feelings/pain in the past week but it did not interfere with me sleep or day-to-day activities.
2 = I experienced occasional uncomfortable feelings/pain that somewhat interfered with my sleep or day-to-day activities.
3 = I experienced uncomfortable feelings/pain on most days in the past week and it significantly interfered with my sleep or my day-to-day activities.
4 = I was hardly able to sleep or do any day-to-day activities in the past week because of the uncomfortable feelings/pain that I felt.

BLADDER INCONTINENCE
Over the past week, have you had trouble with urine control? How often did you feel the urgent need to urinate? Did you feel the need to urinate very often? Did you have some urine accidents?
0 = I had no urine control problems in the past week.
1 = Once or twice only in the past week, I felt the urgent need to urinate or I woke up several times during the night to urinate, but I did not have any urine accidents.
2 = On at least half the days or nights in the past week, I had urinary problems, but I did not have any urinary accidents.
3 = I experienced urinary problems almost every day in the past week, and occasionally, I would have an accident.
4 = I cannot control my urine and I use a protective garment or have a bladder tube.

FATIGUE
Over the past week, on average, did you feel tired or worn out? Did this affect your day-to-day activities?
0 = I did not experience excessive tiredness in the past week.
1 = I experienced slight fatigue in the past week. However, it does not create interference in my ability to carry out daily routines.
2 = The fatigue I experienced in the past week occasionally interfered but did not prevent my ability to carry out daily routines.
3 = The fatigue I experienced in the past week caused me a lot of problems and significantly interfered with my ability to carry out daily routines.
4 = I could hardly do any of my activities in the past week because of fatigue.

SALIVA & DROOLING
Over the past week, did you notice some drooling?
0 = I had no problems with excess saliva and drooling.
1 = I could feel excess saliva in the mouth but did not drool during sleep or when awake.
2 = I had some drooling during sleep, but none when I was awake.
3 = I had some drooling even when I was awake.
4 = I was constantly drooling.

Total subscale score: _______

PART IV: ACTIVITIES OF DAILY LIVING (Patient/Caregiver-Administered)
There are 10 items to be scored.
Patient (or Caregiver) Instructions: We would like to ask you questions about how certain problems may be affecting your day-to-day activities. Please choose the best response that describes how you felt ON AVERAGE during the PAST WEEK including today. It is possible that some of these questions will not apply to you now or ever, so please do not worry as you respond to these questions. If you are not experiencing these problems you can simply respond NO to the questions.

Who answered this form today? (circle one):
PATIENT
CAREGIVER

If caregiver: What is your relationship to the patient? __________________________

SPEECH
Over the past week, did you have problems with your speech?
0 = Not at all (no problems).
1 = My speech was soft, slurred or uneven, but I was not asked to repeat myself.
2 = My speech caused people to asked me to occasionally repeat myself.
3 = My speech was unclear enough that others asked me to repeat myself almost every day.
4 = My speech could not be understood almost all the time.

CHEWING AND SWALLOWING
Over the past week, have you had problems drinking, swallowing or eating? Do you need pills cut or crushed or your food made to be soft, chopped or blended?
0 = No problems
1 = I was aware of slowness when chewing or increased effort when swallowing but I did not choke and I did not need to have food specially prepared or modified.

2 = I choked once or twice in the past week but my food or drink has not been modified.

3 = I choke occasionally at least once a week and my food had to be modified to prevent choking.

4 = Because of drinking, chewing or swallowing problems, I needed a feeding tube.

**EATING/FEEDING**

*Over the past week, have you usually had trouble handling your food and using eating utensils? Do you have trouble handling finger foods or using forks, knives, spoons or chopsticks?*

0 = Not at all (no problems).

1 = I was somewhat slow, but I do not need any help handling my food and have not had food spills while eating.

2 = I was slow with my eating and had occasional food spills. I may have needed help with a few tasks such as cutting food into smaller portions.

3 = I needed help with many eating tasks but could manage some alone.

4 = I was unable to use my hands and was only able to get food using my mouth or I needed help for most or all eating tasks.

**DRESSING**

*Over the past week, did you have problems dressing? Were you slow or did you need help with buttoning, using zippers, putting on or taking off?*

0 = Not at all (no problems).

1 = I was somewhat slow but I did not need help.

2 = I was slow and needed help for a few dressing tasks (buttons).

3 = I needed help for many dressing tasks.

4 = I needed help for most or all dressing tasks.

**HYGIENE**

*Over the past week, did you need help with washing, bathing, shaving, brushing teeth, combing your hair or with other personal hygiene?*

0 = Not at all (no problems).

1 = I was somewhat slow but I did not need any help.

3 = I needed someone else to help me with some hygiene tasks.

4 = I needed help for many hygiene tasks.

5 = I needed help for most or all of my hygiene tasks.

**HANDWRITING**

*Over the past week, did people have trouble reading your handwriting?*

0 = Not at all (no problems).

1 = My writing was slow, clumsy or uneven, but all words were easy to read.

2 = Some words were difficult to read.

3 = Many words were difficult to read.

4 = Most or all words could not be read.

**DOING HOBBIES AND OTHER ACTIVITIES**

*Over the past week, did you have trouble doing your hobbies or other things that you like to do?*

0 = Not at all (no problems).

1 = I was a bit slow but did these activities easily.

2 = I had some difficulty doing these activities.

3 = I had major problems doing these activities, but still did most.

4 = I was unable to do most or all of these activities.

**TURNING IN BED**

*Over the past week, did you have trouble turning over in bed?*

0 = Not at all (no problems).

1 = I had a bit of trouble turning, but I did not need any help.

2 = I had a lot of trouble turning and needed occasional help from someone else.

3 = To turn over I often needed help from someone else.

4 = I was unable to turn over without help from someone else.

**TRANSFERING/GETTING OUT OF BED, A DEEP CHAIR OR VEHICLE**

*Over the past week, did you have trouble getting out of bed, a vehicle, or a deep chair?*

0 = Not at all (no problems).
1 = I was slow or awkward, but I usually could do it on my first try.
2 = I needed more than one try to get up or needed occasional help.
3 = I sometimes needed help to get up, but most of the times I could still do it on my own.
4 = I needed help most or all of the time.

WALKING AND BALANCE
Over the past week, did you have problems with balance and walking?
0 = Not at all (no problems).
1 = I was slightly slow or may have dragged a leg. I never used a walking aid (cane, walker).
2 = I occasionally used a walking aid, but I did not need any help from another person.
3 = I usually used a walking aid to walk safely without falling. However, I did not usually need the support of another person.
4 = I usually used the support of another person to walk safely without falling.

Total Subscale Score: ________

TOTAL SCORE: ____ + ____ + ____ + ____ + ____ = _______

V Global Rating

Global Severity: Interviewer's judgment of the overall severity of the patient's illness. This should focus on the overall burden of the patient's symptoms with respect to its impact on daily functioning (e.g., sleep; ability to work; ability to relate to others) and/or the overall severity of illness/symptoms. In the instance that severity is greater than interference (or interference greater than severity), rate according to the most severe or impaired domain. Rated from 1 (no illness) to 7 (most severe patient seen). (Consider the degree of distress reported by the patient or caregiver, the symptoms observed, and the functional impairment reported. Your judgment is required both in averaging this data as well as weighing the reliability or accuracy of the data obtained. This judgment is based on information obtained during the interview.)

NORMAL, NOT ILL: no illness
BORDERLINE: Subtle illness with minimal, if any functional impairment
MILDLY ILL: Clearly established symptoms with minimal, if any difficulty in function
MODERATELY ILL: Overt symptoms causing noticeable but modest functional impairment and difficulty with goal directed activities
MARKEDLY ILL: Intrusive symptomatology that distinctly impairs social/occupational function and goal directed activities
SEVERELY ILL: Disruptive symptoms; function is frequently influenced by symptomatology and often requires supervision
EXTREMELY ILL: Symptoms drastically interfere in many life functions; incapable of goal-directed activities

Global Improvement Symptoms: Rate total overall improvement present since the initial rating whether or not, in your judgment, it is due to treatment.

VERY MUCH IMPROVED: Nearly all symptoms got better; good level of functioning; minimal symptoms; represents a very substantial change
MUCH IMPROVED: Notably better with significant reduction of symptoms; increase in the level of functioning but some symptoms remain
MINIMALLY IMPROVED: Slightly better with little or no clinically meaningful reduction of symptoms; represents very little change in basic clinical status, level of care, or functional capacity
NO CHANGE: Symptoms remain essentially unchanged
MINIMALLY WORSE: Slightly worse but may not be clinically meaningful; may represent very little change in basic clinical status or functional capacity
MUCH WORSE: Clinically significant increase in symptoms and diminished functioning
VERY MUCH WORSE: Severe exacerbation of symptoms and loss of functioning