Clinician Surveys

Biosamples

Date of Most Recent Examination

Question Text	Responses
Have you ever saved biosamples from this patient?	Yes No
What type of samples have you saved?	Whole Blood Saliva Buccal swab Skin biopsy, please specify tissue
Saved biosamples other than those listed above (specify)	Free text

Question Text	Responses
Contact Name	Free text
Phone Number	Free text
Email Address	Free text

Color, Contrast, and Night Vision

Date of Most Recent Examination

Question Text	Responses
Dark-adapted threshold	Normal Abnormal
Contrast sensitivity	Normal Abnormal
Color vision	Normal Monochromic Dichromic
If Dichromic, select:	Protanopia Deuteranopia Tritanopia Anomalous trichromacy
If Anomalous trichromacy, select:	Protanomaly Deuteranomaly Tritanomaly

Diagnosis and Co-morbidities (REQUIRED for IRB Approved Genetic Testing Study)

Date of Most Recent Examination

Question Text	Responses
Primary retinal condition	Not applicable No Clear Diagnosis Achromatopsia Adult Vitelliform Macular Dystrophy Age-Related Macular Degeneration - Dry Age-Related Macular Degeneration - Mixed Wet and Dry Age-Related Macular Degeneration - Wet Alstrom Syndrome

	Bardet-Biedl Syndrome (Laurence-Moon Syndrome) Bassen-Kornzweig Syndrome Batten Disease Best Disease Bietti Crystalline Dystrophy Blue Cone Monochromacy Charcot-Marie-Tooth Disease Choroidal Dystrophy Choroideremia Coats Plus Syndrome Cohen Syndrome Cone Dystrophy Cone-Rod Dystrophy Congenital Stationary Night Blindness Enhanced S-Cone Syndrome Fundus Albipunctatus Fundus Flavimaculatis Gyrate Atrophy Jalili Syndrome Joubert Syndrome Knobloch Syndrome Late-Onset Retinal Degeneration Leber Congenital Amaurosis Macular Dystrophy Macular Dystrophy - Juvenile Inherited Mainzer-Saldino Syndrome Mallatia Leventinese North Carolina Macular Dystrophy Oculo-Auricular Syndrome Oguchi Disease Pattern Dystrophy PHARC Poretti-Boltshauser Syndrome Refsum Syndrome Retinitis Pigmentosa Retinitis Pigmentosa - Atypical Retinitis Punctata Albescens Rod Dystrophy Rod Monochromacy Rod-Cone Dystrophy ROSAH Syndrome Senior-Loken Syndrome Sorsby Fundus Dystrophy Stargardt Disease Usher Syndrome - Type I Usher Syndrome - Type II Usher Syndrome - Type III Usher Syndrome - Type Unknown Wagner Syndrome X-linked Retinoschisis Other - please specify
Syndromic Diagnosis	Alstrom Syndrome Bardet-Biedl Syndrome (Laurence-Moon) Bassen-Kornzweig Syndrome Batten Disease Enhanced S-Cone Syndrome

	Jalili Syndrome Joubert Syndrome Refsum Syndrome Senior-Loken Syndrome Usher Syndrome - Type Unknown Usher Syndrome - Type I Usher Syndrome - Type II Usher Syndrome - Type III Unknown Other Not Applicable
Associated Medical Conditions - please check all that apply	Not Available No Significant Medical Non-ocular Issue Hearing Deficit High Blood Pressure Neurological Disease Kidney Anomaly Diabetes Developmental Delay Cognitive Impairment Digit Anomaly Psychiatric Disease Asthma Psoriasis Crohn's Disease Multiple Sclerosis Rheumatoid Arthritis Other (Please specify. List and separate by commas
Secondary Retinal Diagnosis	Not applicable Achromatopsia Adult Vitelliform Macular Dystrophy Alstrom Syndrome Age-Related Macular Degeneration - Dry Age-Related Macular Degeneration - Wet Age-Related Macular Degeneration - Mixed Wet and Dry Bardet-Biedl Syndrome (Laurence-Moon Syndrome) Bassen-Kornzweig Syndrome Batten Disease Best Disease Bietti Crystalline Dystrophy Blue Cone Monochromacy Choroideremia Cone Dystrophy Cone-Rod Dystrophy Congenital Stationary Night Blindness Enhanced S-Cone Syndrome Gyrate Atrophy Joubert Syndrome Macular Dystrophy - Juvenile Inherited Leber Congenital Amaurosis Macular Dystrophy North Carolina Macular Dystrophy Oguchi Disease Pattern Dystrophy

	Refsum Syndrome Retinitis Pigmentosa Retinitis Pigmentosa - Atypical Retinitis Punctata Albescens X-linked Retinoschisis Rod-Cone Dystrophy Rod Monochromacy Senior-Loken Syndrome Sorsby Fundus Dystrophy Stargardt Disease Usher Syndrome - Type Unknown Usher Syndrome - Type I Usher Syndrome - Type II Usher Syndrome - Type III Other - please specify Charcot-Marie-Tooth Disease Choroidal Dystrophy Coats Plus Syndrome Cohen Syndrome Fundus Albipunctatus Fundus Flavimaculatis Jalili Syndrome Knobloch Syndrome Late-Onset Retinal Degeneration Mainzer-Saldino Syndrome Mallatia Leventinese PHARC Poretti-Boltshauser Syndrome Rod Dystrophy ROSAH Syndrome Oculo-Auricular Syndrome Wagner Syndrome No Secondary Diagnosis

ERG (Full Field)

Date of Most Recent Examination

Question Text	Responses
Summary of Results?	Normal Abnormal Not Recordable
ISCEV Standard (if reported)	Yes No Other, please state

Question Text	Responses
Scotopic Rod b Wave - Amplitude - OD	Unselected Normal Abnormal Not Recordable
Scotopic Rod b Wave - Amplitude - OS	Unselected Normal Abnormal Not Recordable

Scotopic Rod b Wave - Implicit Time - OD	Unselected Normal Abnormal Not Recordable
Scotopic Rod b Wave - Implicit Time - OS	Unselected Normal Abnormal Not Recordable
Rod/cone a-wave - Amplitude - OD	Unselected Normal Abnormal Not Recordable
Rod/cone a-wave - Amplitude - OS	Unselected Normal Abnormal Not Recordable
Rod/cone b-wave - Amplitude - OD	Unselected Normal Abnormal Not Recordable
Rod/cone b-wave - Amplitude - OS	Unselected Normal Abnormal Not Recordable
Cone b-wave - Amplitude - OD	Unselected Normal Abnormal Not Recordable
Cone b-wave - Amplitude - OS	Unselected Normal Abnormal Not Recordable
Cone b-wave - Implicit Time - OD	Unselected Normal Abnormal Not Recordable
Cone b-wave - Implicit Time - OS	Unselected Normal Abnormal Not Recordable
Photopic 30 Hz Flicker - Amplitude - OD	Unselected Normal Abnormal Not Recordable
Photopic 30 Hz Flicker - Amplitude - OS	Unselected Normal Abnormal Not Recordable
Photopic 30 Hz Flicker - Implicit Time - OD	Unselected Normal Abnormal Not Recordable
Photopic 30 Hz Flicker - Implicit Time - OS	Unselected Normal Abnormal Not Recordable

EZ Width

Date of Most Recent Examination

Question Text	Responses
Eye being measured	OD OS
Date of Most Recent Measurement	MM/YYYY 1930 - 2020
OCT Imaging System	Heidelberg NIDEK Optos Optovue Topcon ZEISS Optional - Specific
Disease state of eye being measured	Better eye Worse eye Eyes similar
Is the end of the EZ band beyond the edge of the scan?	Yes No
Is there a visible EZ band?	Detectable Non-detectable
EZ band width (in mm) - horizontal midline (mm)	0 - 5000mm
EZ band width (in mm) - vertical midline (mm)	0 - 5000mm

Question Text	Responses
Eye being measured	OD OS
Date of Most Recent Measurement	MM/YYYY 1930 - 2020
OCT Imaging System	Heidelberg NIDEK Optos Optovue Topcon ZEISS Optional - Specific
Disease state of eye being measured	Better eye Worse eye Eyes similar
Is the end of the EZ band beyond the edge of the scan?	Yes No
Is there a visible EZ band?	Detectable Non-detectable
EZ band width (in mm) - horizontal midline (mm)	0 - 5000mm
EZ band width (in mm) - vertical midline (mm)	0 - 5000mm

Genetic Diagnosis

Date of Genetic Diagnosis

Question Text	Responses
Is there a family inheritance pattern?	Yes No Unknown Waiting for Results

What is the suspected mode of inheritance?	Unknown Autosomal Dominant (AD) Autosomal Recessive (AR) X-Linked (XL) Isolated / Simplex / Sporadic
Number of disease related variations identified?	0 1 2 3 4 5 6 7 8 9 10
Is this person participating in the My Retina Tracker Genetic Testing Study?	Yes No
Is this diagnosis based on phase testing of relatives?	Yes No
If this diagnosis was not based on phase testing, do you recommend phase testing to clarify this diagnosis?	No Yes
If phase testing is recommended, list the specific variants to be tested:	Free text
Have any variants been reported for this patient?	Yes No

Question Text	Responses
Date of Genetic Diagnosis	MM/YYYY 1930 - 2020
Reference Gene Sequence (example: NM_006445)	Free text
Gene Name **If gene is not listed above, please type the name of the gene in the box**	ABCA1 ABCA4 ABCC6 ABHD12 ACACB ACBD5 ACO2 ADAM9 ADAMTS18 ADGRV1 ADIPOR1 AFG3L2 AGBL5 AHI1 AHR AIPL1 ALMS1 APOE ARAFGAP2 ARFGAP2 ARHGEF18 ARL2BP ARL3 ARL6 ARMS2 ARSG

ASRGL1
ATF6
ATXN7
BBIP1
BBS1
BBS10
BBS12
BBS2
BBS4
BBS5
BBS7
BBS9
BCAMD
BEST1
C12orf65
C1B2
C1QTNF5
C2
C21orf2
C3
C5AR2
C8orf37
CA4
CABP4
CACNA1F
CACNA2D1
CACNA2D4
CAPN5
CC2D2A
CCDC66
CCT2
CDH23
CDH3
CDHR1
CEP164
CEP19
CEP250
CEP290
CEP78
CERKL
CFB
CFH
CFHR1
CFHR3
CHM
CIB2
CLCC1
CLN3
CLRN1
CLUAP1
CNGA1
CNGA3
CNGB1
CNGB3
CNNM4
COL11A1
COL2A1

COL9A1
CORD17
CRB1
CRB2
CRX
CSPP1
CTNNA1
CWC27
CYP4V2
DFNB31
DHDDS
DHX38
DMD
DRAM2
DTHD1
EFEMP1
ELOVL1
ELOVL4
EMC1
ERCC6
ESPN
EXOSC2
EYS
FAM161A
FBLN5
FBN3
FLVCR1
FSCN2
FZD4
GDF6
GNAT1
GNAT2
GNB3
GNPTG
GPR125
GPR179
GPR98
GPR98 (USH2B)
GRK1
GRM6
GUCA1A
GUCA1B
GUCY2D
HARS
HGSNAT
HK1
HMCN1
HMX1
HTRA1
IDH3A
IDH3B
IFT140
IFT172
IFT27
IFT81
IMPG1
IMPG2

INPP5E
INVS
IQCB1
ITM2B
JAG1
KCNJ13
KCNV2
KIAA1549
KIF11
KIZ
KLHL7
KSS
LAMA1
LCA5
LHON
LIPC
LRAT
LRIT3
LRP5
LZTFL1
MAK
MAPKAPK3
MERTK
MFN2
MFRP
MFSD8
MIR204
MKKS
MKS1
MT-ATP6
MT-TH
MT-TL1
MT-TP (Not MTTP)
MTTP (not MT-TP)
MT-TS2
MVK
MYO7A
NBAS
ND1 (MT-ND1)
ND4 (MT-ND4)
ND5 (MT-ND5)
ND6 (MT-ND6)
NDP
NEK2
NEUROD1
NMNAT1
NPHP1
NPHP3
NPHP4
NR2E3
NR2F1
NRL
NYX
OAT
OFD1
OPA1
OPA3

OPA8
OPN1LW
OPN1MW
OPN1SW
OR2W3
OTX2
PANK2
PAX2
PCARE
PCDH15
PCYT1A
PDE6A
PDE6B
PDE6C
PDE6G
PDE6H
PDZD7
PEX1
PEX2
PEX6
PEX7
PGK1
PHYH
PIM1
PITPNM3
PLA2G5
PLK1S1
PLK4
PNPLA6
POC1B
POC5
POMGNT1
PRCD
PRDM13
PROM1
PRPF3
PRPF31
PRPF4
PRPF6
PRPF8
PRPH2
PRPS1
RAB28
RAX2
RB1
RBP3
RBP4
RCBTB1
RD3
RDH11
RDH12
RDH5
REEP6
RGR
RGS9
RGS9BP
RHBDD2

RHO
RIMS1
RLBP1
ROM1
RP1
RP10
RP1L1
RP2
RP63
RP9
RPE65
RPGR
RPGRIP1
RPGRIP1L
RS1
RTN41P1
RTN4IP1
SAG
SAMD11
SCAPER
SDCCAG8
SEMA4A
SF3B2
SLC24A1
SLC25A46
SLC7A14
SNRNP200
SPATA7
SPP2
TEAD1
TIMM8A
TIMP3
TLR3
TLR4
TMEM126A
TMEM237
TOPORS
TREX1
TRIM32
TRNT1
TRPM1
TSPAN12
TTC8
TTLL5
TTPA
TUB
TUBGCP4
TUBGCP6
TULP1
UNC119
USH1A
USH1C
USH1E
USH1G
USH1H
USH1K
USH2A

	USH2ALI VCAN VPS13B WDPCP WDR19 WFS1 ZNF408 ZNF423 ZNF513
Zygosity?	Homozygous (two identical mutations reported) Heterozygous (one mutation reported) Compound heterozygote (two different mutations reported) Hemizygous (one X-linked mutation reported in a male) Unknown / other
Disease Causing?	Pathogenic / Deleterious Probable / Likely pathogenic Unlikely Unknown / Uncertain Not
cDNA sequence change (example: c.305G>A)	Free text
Protein sequence change (example: p.(Arg102Gln))	Free text
Impact of mutation (if reported)	Free text
Additional annotations not previously captured or comments	Free text
Have additional variants been reported for this patient?	Yes No

Kinetic Visual Field

Date of Most Recent Examination

Question Text	Responses
Instrument Used	Goldman Octopus 101 Octopus 900 Other, please state
Smallest Target Stimulus Type - OD	I4e II4e III4e IV4e V4e Not Done
Largest Target Stimulus Type - OD	I4e II4e III4e IV4e V4e Not Done
Primary Pattern of Field Loss - OD	Normal Central Scotoma Para Central Scotoma Annular Scotoma Central Island

	Peripheral Island Other, please state
Smallest Target Stimulus Type - OS	I4e II4e III4e IV4e V4e Not Done
Largest Target Stimulus Type - OS	I4e II4e III4e IV4e V4e Not Done
Primary Pattern of Field Loss - OS	Normal Central Scotoma Para Central Scotoma Annular Scotoma Central Island Peripheral Island Other, please state
Primary Pattern of Field Loss - Vertical diameter of central field - OD	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Primary Pattern of Field Loss - Vertical diameter of central field - OS	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Primary Pattern of Field Loss - Horizontal diameter of central field - OD	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Primary Pattern of Field Loss - Horizontal diameter of central field - OS	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Primary Pattern of Field Loss - Vertical diameter of central scotoma - OD	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees

Primary Pattern of Field Loss - Vertical diameter of central scotoma - OS	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Primary Pattern of Field Loss - Horizontal diameter of central scotoma - OD	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Primary Pattern of Field Loss - Horizontal diameter of central scotoma - OS	Normal <5 degrees <10 degrees <20 degrees <50 degrees <100 degrees <120 degrees
Other Field Loss: Target Stimulus Type - OD	I4e II4e III4e IV4e V4e
Other Field Loss Observation - OD	Central Scotoma Para Central Scotoma Annular Scotoma Central Island Peripheral Island
Other Field Loss: Target Stimulus Type - OS	I4e II4e III4e IV4e V4e
Other Field Loss Observation - OS	Central Scotoma Para Central Scotoma Annular Scotoma Central Island Peripheral Island
Additional Observations on Pattern of Visual Field Loss	Free text

mfERG

Date of Most Recent Examination

Question Text	Responses
ISCEV Standard (if reported)	Yes No Other, please state
Result - OD	Not done Normal Abnormal Not recorded

Result - OS	Not done Normal Abnormal Not recorded

Ocular Assessment

Date of Most Recent Examination

Question Text	Responses
Cataract - OD	Yes No Pseudokphakia Aphakia Not Applicable
Cataract - OS	Yes No Pseudokphakia Aphakia Not Applicable
Cataract Severity - OD	Mild Moderate Severe Not Applicable
Cataract Severity - OS	Mild Moderate Severe Not Applicable
Cornea - OD	Normal Crystals Keratonus
Cornea - OS	Normal Crystals Keratonus
Optic Disc - OD	Normal Pale Abnormal Optic Atrophy Drusen
Optic Disc - OS	Normal Pale Abnormal Optic Atrophy Drusen
Macula - OD	Normal Abnormal Not Done Atrophy Edema Bulls Eye Wrinkling Drusen Flecks Exudates Other Deposits

	RPE Changes Schisis Other finding, please state
Macula - OS	Normal Abnormal Not Done Atrophy Edema Bulls Eye Wrinkling Drusen Flecks Exudates Other Deposits RPE Changes Schisis Other finding, please state
Retina - OD	Normal Abnormal Not Done Peripheral Schisis Bone Spicules Pigment Clumping White Dots Flecks Drusen Retinal detachment Mottling Other finding, please state
Retina - OS	Normal Abnormal Not Done Peripheral Schisis Bone Spicules Pigment Clumping White Dots Flecks Drusen Retinal detachment Mottling Other finding, please state
IVFA - OD	Done Not Done
IVFA - OS	Done Not Done
Autofluorescence - OD	Done Not Done
Autofluorescence - OS	Done Not Done
OCT - OD	Normal Abnormal Not Done Schisis Edema Atrophy
OCT - OS	Normal

	Abnormal Not Done Schisis Edema Atrophy
OCT Volume Scan	Free text

Refraction and Visual Acuity (REQUIRED for IRB Approved Genetic Testing Study)

Date of Most Recent Examination

Question Text	Responses
Correction - OD	High Hyperopic (more than 4) Mid Hyperopic (2 to 4) Emmetropic Mild Myopia Moderate Myopia (-2 to -5) High Myopia (more than -6) None
Correction - OS	High Hyperopic (more than 4) Mid Hyperopic (2 to 4) Emmetropic Mild Myopia Moderate Myopia (-2 to -5) High Myopia (more than -6) None
Astigmatism - OD	None 1.5D 1.5 - 3.0D >3.0D
Astigmatism - OS	None 1.5D 1.5 - 3.0D >3.0D

Question Text	Responses
Which scale will you report for BCVA - 20 feet, 10 feet, 6m or 3m?	20 feet 10 feet 6m 3m (2)
20 Feet - OD	20/12 20/16 20/20 20/25 20/32 20/40 20/50 20/63 20/80 20/100 20/125 20/160 20/200 20/250 20/300

	20/400 20/500 20/600 20/800 20/1000 CF HM LP NLP
10 Feet - OD	10/6 10/8 10/10 10/12 10/16 10/20 10/25 10/32 10/40 10/50 10/63 10/80 10/100 10/125 10/150 10/200 10/250 10/300 10/400 10/500 CF HM LP NLP
6 Meters - OD	6/3.8 6/4.8 6/6 6/7.5 6/9.5 6/12 6/15 6/19 6/24 6/30 6/38 6/48 6/60 6/75 6/95 6/126 6/150 6/190 6/240 6/300 CF HM LP NLP

3 Meters - OD	3/1.9 3/2.4 3/3 3/4 3/5 3/6 3/7 3/9 3/12 3/15 3/19 3/24 3/30 3/37 3/47 3/63 3/75 3/95 3/120 3/150 CF HM LP NLP
20 Feet - OS	20/12 20/16 20/20 20/25 20/32 20/40 20/50 20/63 20/80 20/100 20/125 20/160 20/200 20/250 20/300 20/400 20/500 20/600 20/800 20/1000 CF HM LP NLP
10 Feet - OS	10/6 10/8 10/10 10/12 10/16 10/20 10/25 10/32 10/40

	10/50 10/63 10/80 10/100 10/125 10/150 10/200 10/250 10/300 10/400 10/500 CF HM LP NLP
6 Meters - OS	6/3.8 6/4.8 6/6 6/7.5 6/9.5 6/12 6/15 6/19 6/24 6/30 6/38 6/48 6/60 6/75 6/95 6/126 6/150 6/190 6/240 6/300 CF HM LP NLP
3 Meters - OS	3/1.9 3/2.4 3/3 3/4 3/5 3/6 3/7 3/9 3/12 3/15 3/19 3/24 3/30 3/37 3/47 3/63 3/75 3/95

	3/120 3/150 CF HM LP NLP

Static Visual Field

Date of Most Recent Examination

Question Text	Responses
Name of Instrument Used	Humphrey Octopus 101 Octopus 900 Other, please state
Threshold	SITA 4-2-1 Gate
Stimulus Size	3 4 5 6
Type - OD	30-2 24-2 10-2 Full Field Custom Field Not Done
Type - OS	30-2 24-2 10-2 Full Field Custom Field Not Done
Result - OD	Central Scotoma Normal Para Central Scotoma Annular Scotoma Concentric Constriction Central Island Other, please state
Result - OS	Central Scotoma Normal Para Central Scotoma Annular Scotoma Concentric Constriction Central Island Other, please state
MD (Mean Deviation) - OD (decibels)	-100 - +100 decibels
MD (Mean Deviation) - OS (decibels)	-100 - +100 decibels