Member Surveys

Assistive Devices

Question Text	Responses
Do you use a magnifier to help your vision?	Yes
	No
At what age did you start to use a magnifier?	Unsure
	1 - 89
Do you use computer software to enlarge text?	Yes
	No
At what age did you start using the computer software?	Unsure
	1 - 89
Do you use computer software to read text to you?	Yes
	No
At what age did you start to use computer software to read text to	Unsure
you?	1 - 89
Do you use a white cane?	Yes
	No
At what age did you start to use a white cane?	Unsure
	1 - 89
Do you use a guide dog?	Yes
	No
At what age did you start to use a guide dog?	Unsure
	1 - 89
Do you use a hand held reader?	Yes
	No
At what age did you start using a hand held reader?	Unsure
	1 - 89
Do you use Braille?	Yes
	No
At what age did you start to use Braille?	Unsure
	1 - 89
Do you use a prosthetic device (examples: Argus II, IRIS II, Alpha IMS)?	Yes
	No
At what age did you start using a prosthetic device?	No Unsure

Current Clinical Trial Participation

Question Text	Responses
Are you currently participating in a clinical trial for your retinal	Yes
disease?	No
	Don't know
	Refused
Where (city name) do you go for your clinic visits while participating in the study?	Free text
What type of treatment is being studied in your clinical trial?	Gene therapy
	Stem cell therapy
	Other
What is the name of the clinical trial you are participating in?	Free text

Diagnosis

Question Text	Responses
How old were you when you first began experiencing symptoms with	Prenatal
your eyes?	At birth
, ou. 5, 551	After birth but before 1st birthday
	1 - 99
Which of the following best describes your CURRENT diagnosis?	Not applicable
which of the following best describes your connectiful diagnosis.	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

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 Which other diagnoses have you received prior to today? Select all Not applicable that apply. 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
Have you had genetic testing to confirm your diagnosis?	Yes
	No
	Unknown
Have you been told you have Bare Light Perception (BLP)?	Yes
	No
	Unknown
Have you been told you have No Light Perception (NLP)?	Yes
, , ,	No
	Unknown
How old were you when you received your first clinical diagnosis?	Prenatal
, , ,	At birth
	After birth but before 1st birthday
	1 - 99

Driving

Question Text	Responses
Do you still drive, at least once in a while?	Yes
	No
	Not Applicable - Never drove

Question Text	Responses
How much difficulty do you have driving during the daytime in	No difficulty
familiar places?	A little difficulty
	Moderate difficulty
	Extreme difficulty
How much difficulty do you have driving at night?	No difficulty
	A little difficulty
	Moderate difficulty
	Extreme difficulty
How much difficulty do you have driving in conditions such as bad	No difficulty
weather, on the freeway or in heavy traffic?	A little difficulty
	Moderate difficulty
	Extreme difficulty

Question Text	Responses
If you have stopped driving, what was the reason?	Mainly eyesight
	Mainly other reasons
	Both eyesight and other reasons

Family History

Question Text	Responses
Which other family members have been diagnosed with the SAME	Unknown
inherited retinal degenerative disease as yours?	None
	Brother
	Daughter
	Father
	Granddaughter
	Grandson
	Half-brother
	Half-sister
	Maternal Aunt
	Maternal Cousin
	Maternal Grandfather
	Maternal Grandmother
	Maternal Uncle
	Mother
	Nephew
	Niece
	Paternal Aunt
	Paternal Cousin
	Paternal Grandfather
	Paternal Grandmother
	Paternal Uncle
	Sister
	Son
Which other family members have been diagnosed with a DIFFEDENT	Unknown
Which other family members have been diagnosed with a DIFFERENT	None
retinal degenerative disease from yours?	Brother
	Daughter Father
	Granddaughter Grandson
	Half-brother
	Half-sister
	Maternal Aunt
	Maternal Cousin
	Maternal Grandfather
	Maternal Grandmother
	Maternal Uncle Mother
	Nephew
	Niece Paternal Aunt
	Paternal Aunt Paternal Cousin
	Paternal Grandfather
	Paternal Uncle
	Paternal Uncle
	Sister
Miles when wateral decreases the Decrease to the Control of the Co	Son
What other retinal degenerative diseases have been diagnosed within	Not applicable
your family?	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

Genetic Testing

Question Text	Responses (Additional Info)
What is the name of the lab that did the genetic testing? Please check	Unsure
all that apply.	Asper Biotech
an that apply.	Blueprint Genetics
	Baylor College of Medicine, Medical
	Genetics Lab, Houston Texas
	Casey Eye Institute Molecular Diagnostics
	Laboratory
	Emory Genetics Lab
	GeneDx, Inc.
	Harvard Center for Personalized Medicine
	Massachusetts Eye and Ear Infirmary,
	Ocular Genomics Inst.
	Molecular Vision Lab, OR
	National Eye Institute - NIH
	Prevention Genetics, Inc.
	UC San Diego, Shiley Eye Center
	Univ. of Colorado, Denver Genetic Lab
	University of Iowa, Carver Laboratories
	Other
Was your disease causing gene identified?	Yes
	No
	Unknown / Uncertain
How many disease causing genes were identified?	1
	2
	3
	4
What is the name of the first gene that was identified as being	ABCA1
disease-causing for your diagnosis?	ABCA4
	ABCC6
This question and following repeated for four genes	ABHD12
	ACACB
	ACBD5
	ACO2
	ADAM9
	ADAMTS18
	ADGRV1
	ADIPOR1
	AFG3L2
	AGBL5
	AHI1
	AHR
	AIPL1
	ALMS1
	APOE
	ARAFGAP2
	ARFGAP2
	A D. I. O. E. F. A. O.
	ARHGEF18
	ARHGEF18 ARL2BP
	ARL2BP
	ARL2BP ARL3 ARL6 ARMS2
	ARL2BP ARL3 ARL6
	ARL2BP ARL3 ARL6 ARMS2

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
Genetic Mutation (first gene) - enter the specific gene mutation if	Free text
known.	
Is the mutation reported as homozygous (first gene)?	Yes
	No
	Unknown
What is the suspected mode of inheritance (first gene)?	Unknown
	Autosomal Dominant (AD)
	Autosomal Recessive (AR)
	X-Linked (XL)
	Isolated / Simplex / Sporadic
	Mitochondrial

General Health

Question Text	Responses
How would you rate your overall health?	Excellent
	Very good
	Good
	Fair
	Poor
Have you ever had any of these medical problems?	Arthritis
	Breathing (asthma, pneumonia, etc.)
	Cancer
	Cataract surgery
	Chronic alcoholism
	Dental disease
	Diabetes
	Glaucoma
	Hearing loss (mild, moderate or severe)
	Hypercholesteremia (high cholesterol in
	blood)
	Hyperlipidemia (high lipid levels in blood)
	Hypertension (high blood presssure)
	Hypotension (low blood pressure)
	Intellectual disability
	Kidney or bladder disease
	Liver disease
	Loss of muscle tone
	Malaria
	Recurring vomiting/diarrhea/constipation
	Seizures
	Skeletal or bone abnormalities
	Thyroid disease
	None
	Other - please state
Do you have difficulty with your hearing?	Yes
	No
	Unsure
Do you have kidney problems?	Yes

Unsure Do you take any over-the-counter medications or dietary supplements? No Unknown Which of the following over-the-counter medications or supplements do you use currently? Britamin Britamin Britamin Britamin Britamin Britamin Choline Coenzyme Q10 (CoQ-10) Creatine Monohydrate Fish oil Folic Acid Grape Seed Extract Green Tea Extract Inositol L-Arginine L-Carnitine Magnesium Melatonin Multivitamin Niacin Omega fatty acid supplement (DHA, EHA) Phosphatidyl Choline Saffron Selenium Taurine TUDCA Vitamin C Vitamin C Vitamin C Vitamin C Vitamin E
supplements? Which of the following over-the-counter medications or supplements do you use currently? Aspirin B vitamin B-12 (methylcobalamine) B-50 Complex Calcium Choline Coenzyme Q10 (CoQ-10) Creatine Monohydrate Fish oil Folic Acid Grape Seed Extract Green Tea Extract Inositol L-Arginine L-Carnitine Magnesium Melatonin Multivitamin Niacin Omega fatty acid supplement (DHA, EHA) Phosphatidyl Choline Saffron Selenium Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
Supplements? Which of the following over-the-counter medications or supplements do you use currently? Aspirin B vitamin B-12 (methylcobalamine) B-50 Complex Calcium Choline Coenzyme Q10 (CoQ-10) Creatine Monohydrate Fish oil Folic Acid Grape Seed Extract Green Tea Extract Inositol L-Arginine L-Carnitine Magnesium Melatonin Multivitamin Niacin Omega fatty acid supplement (DHA, EHA) Phosphatidyl Choline Saffron Selenium Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin C
Which of the following over-the-counter medications or supplements do you use currently? By triamin B-12 (methylcobalamine) B-50 Complex Calcium Choline Coenzyme Q10 (CoQ-10) Creatine Monohydrate Fish oil Folic Acid Grape Seed Extract Green Tea Extract Inositol L-Arginine L-Carnitine Magnesium Melatonin Multivitamin Niacin Omega fatty acid supplement (DHA, EHA) Phosphatidyl Choline Saffron Selenium Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
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Phosphatidyl Choline Saffron Selenium Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
Saffron Selenium Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
Selenium Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
Taurine TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
TUDCA Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
Vitamin A Palmitate (Beta Carotene) Vitamin C Vitamin D
Vitamin C Vitamin D
Vitamin D
Vitamin F
None
Other - please state
Do you have a history of smoking or vaping? Current smoker / vaper
Not a current smoker / vaper but smoked
in the past
Never smoked / vaped regulary
What year did you start smoking or vaping? YYYY – 1900 - 2021
What year did you stop smoking or vaping? YYYY – 1900 - 2021
On average how many cigarettes, cigars, vapes do/did you smoke per Less than 10
day? 10 - 20
20 - 30
30 - 40
More than 40
What type of health insurance do you have?Select all that apply. No insurance
Private health insurance
Medicare (US Only)
Medicaid (US Only)
Other public / government insurance

Hearing

Question Text Responses

What type of hearing loss do you have?	Unsure
	Conductive hearing loss
	Mixed hearing loss
	Sensorineural Hearing Loss (permanent
	nerve hearing loss)
What type of hearing loss do you have?	Unsure
	Conductive hearing loss
	Mixed hearing loss
	Sensorineural Hearing Loss (permanent
	nerve hearing loss)
What is the current status of your conductive hearing loss?	Currently a problem
triat is the current status of your conductive ficulting loss.	Not a problem today, but was in the past
	Never a problem
	Unsure
At what are was your conductive bearing less diagnosed?	
At what age was your conductive hearing loss diagnosed?	Unsure
	0 - 3 months old
	4 -7 months old
	8 - 11 months old
	1 year old - 70 years old
What is the current status of your mixed hearing loss?	Currently a problem
	Not a problem today, but was in the past
	Never a problem
	Unsure
At what age was your mixed hearing loss diagnosed?	Unsure
	0 - 3 months old
	4 -7 months old
	8 - 11 months old
	1 year old - 70 years old
What is the current status of your sensorineural Hearing Loss	Currently a problem
(permanent nerve hearing loss)?	Not a problem today, but was in the past
(permanent nerve nearing 1999).	Never a problem
	Unsure
At what age was your sensorineural hearing Loss (permanent nerve	Unsure
hearing loss) diagnosed?	0 - 3 months old
Theating 1033/ diagnosed.	4 -7 months old
	8 - 11 months old
	1 year old - 70 years old
Milest in the comment status of your bearing less?	Currently a problem
What is the current status of your hearing loss?	, ·
	Not a problem today, but was in the past
	Never a problem
	Unsure
At what age was your hearing loss diagnosed?	Unsure
	0 - 3 months old
	4 -7 months old
	8 - 11 months old
	1 year old - 70 years old
How did this symptom change?	It resolved on its own
	It improved as a result of a treatment
	I have adapted to its presence
	Unsure
What treatment was that?	Free text
Have you ever had a hearing test from an audiologist?	Yes
	No
	Unsure
	J.,JJ, G

Medications Used

Question Text	Responses
Have you ever received or taken a prescription drug or treatment for	Yes
your inherited retinal disease?	No
	Don't know
What is the name of the drugs or treatments you used / were given	Luxturna (Voretigene neparvovec)
for your retinal disease?	Other

Vision Self-evaluation

Question Text	Responses
Do you experience night blindness?	Yes
, ,	No, but I did in the past
	Never a problem
	Unsure
At what age did you become aware of your night blindness?	Unsure
	At birth
	After birth but before 1st birthday
	1 - 99
Do you have reduced peripheral (side) vision loss?	Yes
, , ,	No, but I did in the past
	Never a problem
	Unsure
At what age did you become aware of your loss in peripheral (side)	Unsure
vision loss?	At birth
	After birth but before 1st birthday
	1 - 99
Do you have any loss of central vision?	Yes
•	No, but I did in the past
	Never a problem
	Unsure
At what age did you become aware of your loss in central vision?	Unsure
,	At birth
	After birth but before 1st birthday
	1 - 99
Is your ability to read impaired?	Yes
	No, but I did in the past
	Never a problem
	Unsure
At what age did you become aware of your impaired ability to read?	Unsure
	At birth
	After birth but before 1st birthday
	1 - 99
Do you wear prescription glasses or contact lenses?	Currently I wear them
	I don't currently wear them, but I have in
	the past
	I have never worn them
	Unsure
At what age did you need to start wearing prescription glasses or	Unsure
contact lenses?	At birth
	After birth but before 1st birthday
	1 - 99
Is your ability to see distant objects impaired?	Yes
	No, but I did in the past
	·

	Navana amalalam
	Never a problem
and the first first transfer	Unsure
When did you first become aware of the difficulty in seeing distant	Unsure
objects?	At birth
	After birth but before 1st birthday
	1 - 99
Do you have, or have you ever had, cataracts?	Currently I have them
	I don't currently have them, but I have in
	the past
	Never had cataracts
	Unsure
At what age did you become aware of your cataracts?	Unsure
	At birth
	After birth but before 1st birthday
	1 - 99
Do you have, or have you had, glaucoma?	Currently I have glaucoma
	I don't have glaucoma currently, but I
	have in the past
	I have never had glaucoma
	Unsure
When did you first become aware of your glaucoma?	Unsure
	At birth
	After birth but before 1st birthday
	1 - 99
Have you ever had a detached retina?	Currently a problem
•	Not a problem today, but was in the past
	Never a problem
	Unsure
At what age did you have a detached retina?	Unsure
	At birth
	After birth but before 1st birthday
	1 - 99
Do you have a problem with dark adaptation?	Currently a problem
, , ,	Not a problem today, but was in the past
	Never a problem
	Unsure
When did first harmer a south a set of the color	Unsure
when did you first become aware of your slow dark adaptation?	Unsure
when did you first become aware of your slow dark adaptation?	
wnen ald you first become aware of your slow dark adaptation?	At birth
wnen ald you first become aware of your slow dark adaptation?	At birth After birth but before 1st birthday
	At birth After birth but before 1st birthday 1 - 99
	At birth After birth but before 1st birthday 1 - 99 Currently a problem
	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past
	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem
Do you experience photopsia/random light flashes?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start? Do you have a problem with color vision?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start? Do you have a problem with color vision?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure Unsure Unsure Unsure
When did you first become aware of your slow dark adaptation? Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start? Do you have a problem with color vision? At what age were you first aware of your problem with color vision?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure Unsure Unsure At birth
Do you experience photopsia/random light flashes? At what age did you start to experience photopsia/random light flashes start? Do you have a problem with color vision?	At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure At birth After birth but before 1st birthday 1 - 99 Currently a problem Not a problem today, but was in the past Never a problem Unsure Unsure Unsure Unsure Unsure

Your health today

Question Text	Responses
Are you able to do chores such as vacuuming or yard work?	Without any difficulty
	With a little difficulty
	With some difficulty
	With much difficulty
	Unable to do
Are you able to go up and down stairs at a normal pace?	Without any difficulty
	With a little difficulty
	With some difficulty
	With much difficulty
	Unable to do
Are you able to go for a walk of at least 15 minutes?	Without any difficulty
	With a little difficulty
	With some difficulty
	With much difficulty
	Unable to do
Are you able to run errands and shop?	Without any difficulty
	With a little difficulty
	With some difficulty
	With much difficulty
	Unable to do

Question Text	Responses
In the past 7 daysI felt fearful	Never
	Rarely
	Sometimes
	Often
	Always
In the past 7 daysI found it hard to focus on anything other than my	Never
anxiety	Rarely
	Sometimes
	Often
	Always
In the past 7 daysMy worries overwhelmed me	Never
	Rarely
	Sometimes
	Often
	Always
In the past 7 daysI felt uneasy	Never
	Rarely
	Sometimes
	Often
	Always

Question Text	Responses	
In the past 7 daysI felt worthless	Never	
	Rarely	
	Sometimes	
	Often	
	Always	
In the past 7 daysI felt helpless	Never	
	Rarely	
	Sometimes	
	Often	

	Always
In the past 7 daysI felt depressed	Never
	Rarely
	Sometimes
	Often
	Always
In the past 7 daysI felt hopeless	Never
	Rarely
	Sometimes
	Often
	Always

Question Text	Responses
During the past 7 daysI feel fatigued	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much
During the past 7 daysI have trouble starting things because I am	Not at all
tired	A little bit
	Somewhat
	Quite a bit
	Very much
During the past 7 daysHow run-down did you feel on average?	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much
During the past 7 daysHow fatigued were you on average?	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much

Question Text	Responses
In the past 7 daysMy sleep quality was	Very poor
	Poor
	Fair
	Good
	Very good
In the past 7 daysMy sleep was refreshing	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much
In the past 7 daysI had a problem with my sleep	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much
In the past 7 daysI had difficulty falling asleep	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much

Question Text	Responses
I have trouble doing all of my regular leisure activities with others	Never
	Rarely
	Sometimes
	Usually
	Always
I have trouble doing all of the family activities that I want to do	Never
	Rarely
	Sometimes
	Usually
	Always
I have trouble doing all of my usual work (include work at home)	Never
	Rarely
	Sometimes
	Usually
	Always
I have trouble doing all of the activities with friends that I want to do	Never
	Rarely
	Sometimes
	Usually
	Always

Question Text	Responses
In the past 7 daysHow much did pain interfere with your day to day	Not at all
activities?	A little bit
	Somewhat
	Quite a bit
	Very much
In the past 7 daysHow much did pain interfere with work around	Not at all
the home?	A little bit
	Somewhat
	Quite a bit
	Very much
In the past 7 daysHow much did pain interfere with your ability to	Not at all
participate in social activities?	A little bit
	Somewhat
	Quite a bit
	Very much
In the past 7 daysHow much did pain interfere with your household	Not at all
chores?	A little bit
	Somewhat
	Quite a bit
	Very much

Question Text	Responses
In the past 7 daysI have been able to concentrate	Not at all
	A little bit
	Somewhat
	Quite a bit
	Very much
In the past 7 daysI have been able to remember to do things, like	Not at all
take medicine or buy something I needed	A little bit
	Somewhat
	Quite a bit

very mach	Very much
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Question Text	Responses
In the past 7 daysHow would you rate your pain on average?	0 No pain – 10 Worst pain imaginable