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The Sky I Don’t See

Heather Grizzle · October 8, 2026

Kuv yog Deaf thiab Blind, kuv tsav tsheb, thiab kuv nyiam siv email ntau dua. Sector RP, DeafBlind spectrum, thiab AuDHD piav qhia tau tias vim li cas tej no tsis sib txawv.

Cov Ntsiab Lus

1. Qhov nthuav saum toj
2. Qhov sector RP tiag tiag coj mus
3. Vim li cas kuv hais tias DeafBlind
4. Vim li cas kuv tsav tsheb zoo xwb
5. Vim li cas kuv nyiam email, thiab vim li cas nws tsis yog feem DeafBlind
6. Vim li cas nws yeej pom tsis tau
7. Yam uas kuv thov
8. Cov chaw siv

Kuv yog Deaf, kuv siv ASL, thiab ib hom retinitis pigmentosa tsis tshua pom tau ua rau sab saum toj ntawm kuv qhov muag pom tau raug rhuav tshem lawm. Kuv hu kuv tus kheej tias DeafBlind. Kuv kuj sib ntsib qhov muag, nyeem ntsej muag, tsav tsheb mus rau cov rooj sib tham kuv tus kheej, thiab nyiam xa email. Ntawm no yog vim li cas cov ntsiab lus no tsis sib txawv.

LUV LUV

- Sector RP tau coj mus txhua yam saum qhov qhab nqe tim qhov muag. Kuv qhov pom hauv nruab nrab yog li 20/30 nrog iav tsom muag, thiab nruab nrab thiab qab yog kaj meej.
- DeafBlind describes a spectrum. What defines it is that two losses remove each other's backup, not how little a person can see.
- Minnesota's license test measures the horizontal field only. My loss sits in the one direction it never checks, and the road rarely needs.
- Kuv qhov nyiam xa email los ntawm kuv yog AuDHD, tsis yog los ntawm kuv qhov muag los sis qhov ntsej.

Qhov nthuav saum toj

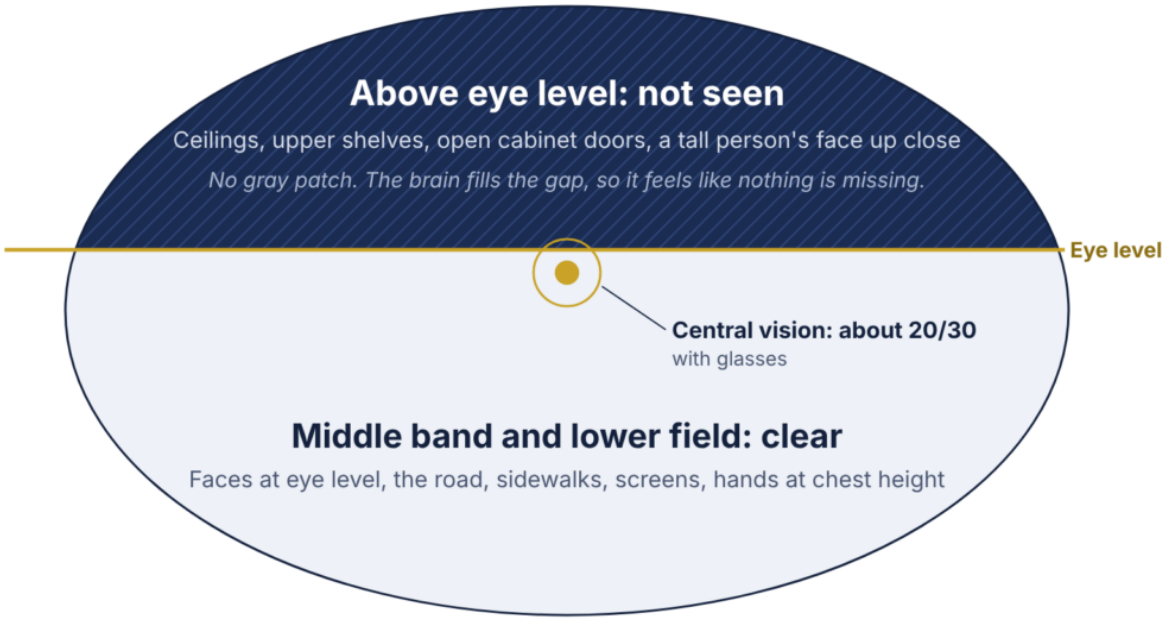
Lub qhov rooj tog zaub mov ntes kuv txhua zaug. Muaj ib tus neeg nyob hauv chav ua noj tso nws qheb, kuv tig ntawm lub dab dej, thiab lub kaum ntawm nws tuaj raug kuv hau ua ntej kuv paub tias nws muaj. Nws tsis yog qhov ua tsis tau zoo, thiab nws kuj tsis yog qhov tsis quav ntsej. Lub qhov rooj yeej nyob saum sab uas kuv lub ntiaj teb kawg ntawm nws. Cov ceg ntoo qis ntawm txoj kev taug, lub kaum ntawm lub thawv hom khoom qhib siab, ib daim npe dai saum nthab ntawm lub tsev khw, ib txhais tes fav kuv los ntawm sab saum xub pwg: txhua yam nyob rau hauv ib qhov ntawm lub ntuj uas kuv tsis pom. Kuv tau taug kev mus thoob plaws ntiaj teb nrog qhov saum toj raug txiav tawm ntau ntau xyoo ntawm kuv txoj sia, thiab yuav luag tsis muaj leej twg nyob ib puag ncig kuv tau pom.

Ntawd yog qhov txawv txog kuv txoj kev tsis taus. Kuv yog Deaf, kuv siv ASL, thiab kuv muaj ib hom retinitis pigmentosa uas tau coj mus sab saum toj ntawm kuv qhov pom. Kuv hu kuv tus kheej tias DeafBlind. Thaum kuv hais li ntawd, cov neeg saib kuv zoo li koj saib ib tug neeg uas tau hais tias nws yog tus tsav dav hlau thaum sawv ntawm DMV. Kuv sib ntsib qhov muag. Kuv nyeem lawv ntsej muag. Kuv tsav tsheb mus rau cov rooj sib tham kuv tus kheej. Kuv teb email ceev dua ntau tus neeg hnov lus uas kuv paub. Tsis muaj ib yam dab tsi txog yuav ua li cas kuv txav hauv ib chav uas qhia tias dig muag, yog li lo lus poob zoo li qhov ua loj dhau lawm, los sis phem dua, zoo li ib qhov kev thov uas kuv tab tom thov rau qee yam txiaj ntsim. Zaj lus no yog kuv txoj kev sim piav qhia txog qhov tiag tiag tab tom tshwm sim, vim qhov sib

txawv ntawm qhov neeg pom thiab qhov kuv nyob dav heev uas kuv nkees ntawm poob rau hauv.

Qhov sector RP tiag tiag coj mus

Retinitis pigmentosa is a family of inherited conditions in which the light-sensing cells of the retina slowly die off. Most people who have heard of it picture the classic version: the field closes in from the edges until a person is looking through a straw. Mine is a rarer variant called sector RP, in which the damage stays confined to one or two quadrants of the retina instead of spreading around the whole ring. In most people with sector RP, and in me, the damaged quadrants are in the lower half of the retina. Because the eye's lens flips the image, damage at the bottom of the retina erases the top of the visual field. Clinical reviews describe exactly this pattern: degeneration along the inferior retina, matching defects in the superior field, and slow progression over years [1].



Illustration, not a clinical visual field test

Kuv thaj chaw pom, kwv yees li. Txhua yam saum qhov qhab nqe poob tag lawm; nruab nrab thiab qab ua haujlwm zoo.

Hais raws li siv tau, qhov no yog qhov kuv muaj. Kuv qhov pom hauv nruab nrab, qhov chaw meej meej uas koj siv los nyeem thiab paub ntsej muag, yog li 20/30 nrog iav tsom muag, uas zoo dua ntau tus neeg uas yeej yuav tsis xav tias lawv tsis taus. Thaj chaw nruab nrab ntawm kuv thiab qab yog kaj meej. Qhov poob yog txhua yam saum qhov qhab nqe. Yog kuv saib ncaj nraim, tsis muaj nthab, tsis muaj saum lub qhov rooj, tsis muaj txaj saum toj, tsis muaj ntsej muag ntawm ib tug neeg siab nyob ze. Tsis muaj ib qhov av dub qhov chaw cov yam ntawd yuav tsum nyob. Hlwb tsis qhia koj lub qhov; nws ua kom nplua, yog li qhov poob tsis xav zoo li poob. Nws xav zoo li tsis muaj dab tsi. Ntawd yog vim li cas lub qhov rooj tog zaub mov yog ib qhov tsis xav txog txhua zaug. Kuv tsis muaj ib qhov dig muag kuv tuaj yeem tig dhau. Kuv muaj ib lub ntiaj teb saib zoo tag nrho tab sis muaj yam khoom nyob rau hauv uas kuv tsis pom kom txog thaum nws ntaus kuv.

Vim li cas kuv hais tias DeafBlind

Kuv xav kom meej meej ntawm no, vim qhov meej meej yog tag nrho cov lus sib cav. Txoj cai raug cai tsim nyog tshaj plaws ntawm deaf-blindness nyob rau hauv Tebchaws Meskas, sau rau hauv Helen Keller National Center Act, yog tsim los ntawm tej lej: qhov pom hauv nruab nrab 20/200 los sis tsawg dua, los sis ib thaj chaw tsis dav tshaj 20 degrees, los sis ib qhov poob nce mus rau ib qho ntawm cov no [2]. Kuv cov lej tsis ze li ntawd, thiab kuv yuav tsis ua zoo li tsis muaj. Yog DeafBlind txhais tau tias tsuas yog cov neeg uas raug txoj cai pej xeem kev tsim nyog, kuv yuav tsis siv lo lus no.

But that is not what the word means to the people who live it. DeafBlind is a spectrum, and the large majority of people on it have some usable vision, some usable hearing, or both. The DeafBlind community has long made a point that the numbers miss: deafblindness is not deafness plus blindness. It is what happens when the two losses remove each other's backup. A hearing person with my exact eyes would hear the cabinet door creak open. A Deaf person with perfect eyes would see it. I get neither

> Ib tug neeg hnov lus nrog qhov poob tsawg ntawm thaj chaw poob saum lub qhov rooj. Kuv poob saum kuv hom lus.
>
> Heather M. Grizzle

channel for that slice of the world. Every piece of information that reaches me comes through vision, and part of my vision is missing.

Leej twg ntes tau yam tshwm sim saum qhov qhab nqe

Lub sij hawm	Ib tug neeg hnov lus nrog kuv qhov muag	Ib tug Deaf nrog qhov muag tag nrho	Kuv
Ib lub qhov rooj tog zaub mov qheb saum kuv	Hnov nws qheb	Pom nws	Tsis muaj ib qho
Muaj ib tug neeg hu los sis fav los ntawm ib txoj kab taug saum lauj kaub	Hnov lawv	Pom qhov fav	Tsis muaj ib qho
Txhais tes nce saum qhov qhab nqe hauv ib qhov kev sib tham siv hom lus	Tsis muaj feem	Pom txhua lo lus	Poob ib feem ntawm kab lus

Qhov chaw: Tus sau tus kheej cov kev paub

Feem hom lus ua kom meej dua. ASL yog ib hom lus pom, thiab nws thaj chaw ua lus khiav los ntawm saum hau mus txog duav. Ib daim ntawv ntev ntawm cov lus yog ua rau ntawm hauv pliaj thiab sab tog taub hau. Thaum ib tug neeg siab ua lus rau kuv nyob ze, qhov saum toj ntawm nws thaj chaw ua lus tuaj yeem poob rau hauv feem ntawm thaj chaw kuv tsis muaj, thiab kuv tab tom tsim cov lus dua los ntawm tej keeb kwm thiab qab ntawm ib daim duab tes. Thaum ib pab pawg ua lus thoob plaws ib chav, kuv poob cov tes uas nce.

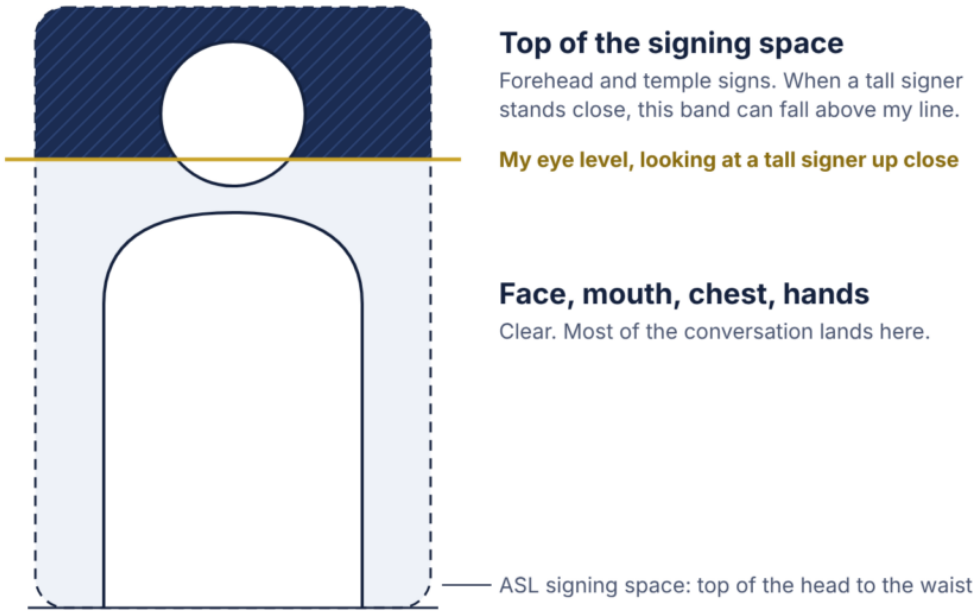


Illustration. How much is lost depends on the signer's height and distance.

ASL thaj chaw ua lus khiav los ntawm saum hau mus txog duav. Nrog ib tug neeg siab ua lus nyob ze, thaj chaw saum toj tuaj yeem poob tawm ntawm kuv qhov pom.

Ib tug neeg hnov lus nrog qhov poob tsawg ntawm thaj chaw poob saum lub qhov rooj. Kuv poob saum kuv hom lus. Ntawd yog vim li cas kuv hais tias DeafBlind. Nws tsis yog ib qhov kev thov txog npaum li cas kuv pom tsis tau. Nws yog ib qhov piav qhia tseeb txog yam tshwm sim thaum tib qhov kev paub xwb uas kuv lub ntiaj teb khiav raws muaj ib feem txiav tawm.

Vim li cas kuv tsav tsheb zoo xwb

The question I get most, sometimes asked out loud and more often asked with a look, is how a DeafBlind woman has a driver's license. The answer is that driving happens almost entirely in the part of the world I can see. The road, the lane lines, the car ahead, the pedestrian stepping off a curb, the mirrors, the dashboard: all of it sits in the horizontal band and the lower field, which are clear for me. Minnesota's licensing rule reflects this. To hold an unrestricted license, a driver needs 20/40 acuity and a field of at least 105 degrees measured across the horizontal diameter [3]. There is no vertical field standard at all.

COV LEJ UAS TSEEM CEEB NTAWM TXOJ KEV

20/30
Kuv qhov pom tseem ceeb nrog iav qhov muag

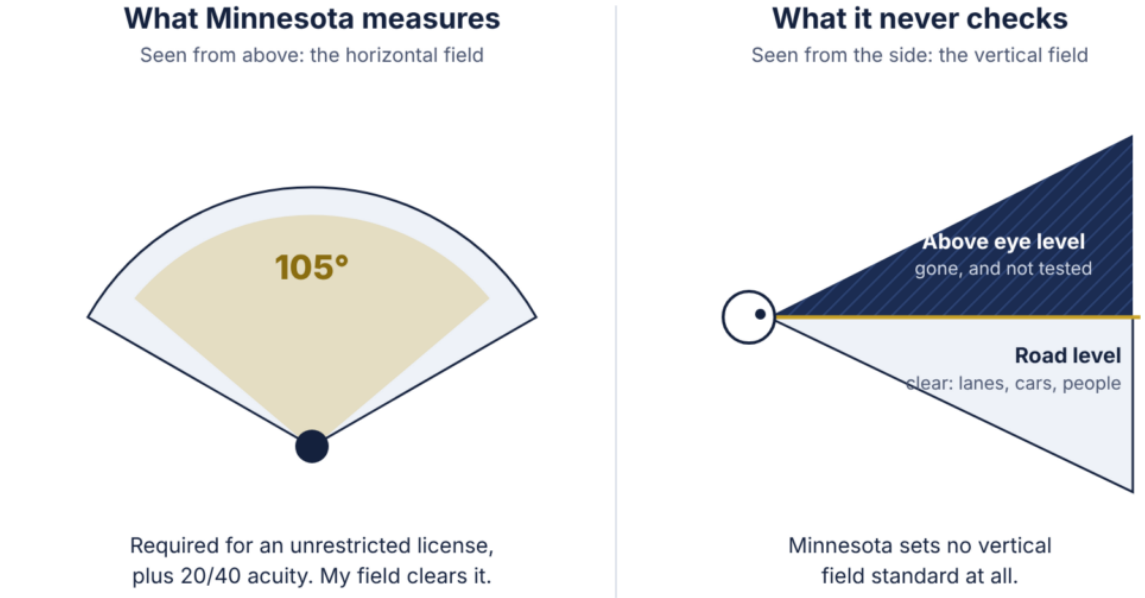
20/40
Minnesota tus qauv rau daim ntawv tsav tsheb uas tsis txwv

105°
Kab dav ntawm sab tav uas lub xeev yuav tsum tau

0
Cov qauv kab siab nyob rau hauv txoj cai

Chaw qhia: Minn. R. 7410.2400; kuv tus kheej qhov kuab qhov muag xeem

Kuv ua tau raws li tus qauv uas lub xeev siv tiag tiag, tseem tshuav chaw ntxiv, vim qhov kuv poob qis nyob rau sab uas qhov kev xeem tsis ntsuas thiab txoj kev tsis ntau zaus nug txog.



Minnesota xeem seb koj pom dav npaum li cas, tsis yog pom siab npaum li cas. Qhov kuv poob qis nyob rau sab uas txoj cai yeej tsis tshuaj xyuas.

The overhead parts of driving are the parts I have learned to handle on purpose. A traffic light or an overhead highway sign sits near the horizon when it is far away, which is exactly when I need to read it, so I read early. As I pull close to a stop line I lift my chin rather than trusting that the signal is still where I last saw it. None of that is heroic adaptation. It is the same kind of habit every driver builds around their own car's blind spots. The irony is that driving is one of the places where my disability matters least, and it is the single fact most likely to convince people I do not have one.

Vim li cas kuv nyiam email, thiab vim li cas nws tsis yog feem DeafBlind

Cov neeg uas paub tias kuv yog DeafBlind thiab paub tias kuv nyiam email feem ntau txuas ob yam no ua ke. Nws ua rau muaj ib zaj dab neeg zoo nkauj: nws pom tsis zoo, nws hnov tsis tau, yog li ntawd nws sau ntawv xwb. Zaj dab neeg ntawd tsis yog qhov tseeb, thiab kuv xav kho nws tsis cia nws nyob li ntawd, vim nws tsis ncaj ncees rau ob yam uas nws muab sib xyaw. Kuv txawj teem lus ntawm kev sib tham video. Kuv txawj nyeem ib lub ntsej muag ntawm lub videophone; tus neeg ntawd nyob rau hauv nruab nrab ntawm kuv, nyob ntawm qhov kuv ntsia ncaj, tseeb nyob rau hauv feem ntawm

kuv qhov pom uas ua haujlwm zoo. Kuv qhov nyiam email tsis ntau tshaj li muaj feem cuam tshuam nrog kuv qhov muag los sis kuv qhov pob ntseg. Nws los ntawm qhov kuv yog AuDHD, autistic thiab ADHD ib yam nkaus.

Live conversation asks for many things at once. I have to take in the language, track the other person′s face and intent, hold my own thoughts in working memory while they keep moving, decide what matters, and answer in real time without the pause that would let me answer well. For my brain, that is not one task; it is five tasks running in parallel, and the cost shows up later as exhaustion and as answers I wish I had given differently. Writing removes the clock. I can read the whole message, let it settle, think it through properly, and send something precise. Many of my best hours of work arrive in deep, focused stretches, and asynchronous exchange lets me meet people inside those stretches instead of being pulled out of them by a call that lands at the wrong moment. Email is not me avoiding people. It is the setting in which I show up as my most competent and most generous self.

> **OB YAM MOB, OB YAM PIAV QHIA**
>
> If I let people believe email is a DeafBlind accommodation, someone eventually watches me sign fluently on a video call and concludes I was exaggerating all along. Each condition deserves its own true explanation, and each is easier to believe when it is not being asked to carry the other′s weight.

Vim li cas nws yeej pom tsis tau

Tag nrho kuv peb yam mob yeej pom tsis tau raws li ib txwm muaj, thiab lawv zais lwm tus. Kev lag ntseg tsis pom tshwm txog thaum kuv pib teem lus. Kuv qhov pom tsis zoo tsis tshwm los kiag li, vim cov feem uas neeg saib, kev ntsia ncaj, kev nyeem, kev taug kev ntawm txoj kev taug, yog cov feem ua haujlwm zoo. Autism thiab ADHD tshwm feem ntau raws li kev nyiam uas zoo li tus cwj pwm: kev nyiam email, kev ncaj qha, qhov yuav tsum nkag siab txoj kev npaj ua ntej kuv thiaj ua tau. Muab sib xyaw ua ke, feem ntau neeg pom kuv zoo li ib tug poj niam Deaf uas muaj peev xwm thiab muaj tswv yim nruj thiab muaj kev sib raug zoo txawv txawv nrog tej qhov qhib tub. Qhov kev pom ntawd tsis yog yuam kev tag nrho. Tsuas yog tsis muaj feem uas piav qhia tias ua li cas kuv thiaj ua li kuv ua.

Peb feem coob tabtom

> mus kev, tsav tsheb, ua haujlwm, thiab teb email, nrog ib daim ntawm peb lub ntiaj teb ploj mus twj ywm.
>
> Heather M. Grizzle

Tus nqi ntawm kev raug neeg nkag siab yuam kev tsis muaj kev ceeb toom, uas yog ib feem ua rau nws nyuaj sib tham txog. Tsis muaj leej twg muab kev pab rau ib qho kev xiam oob khab uas lawv pom tsis tau, yog li kuv ces nug thiab kam txais kev pheej hmoo yuav raug xav tias kuv ua kom loj dhau, los sis kuv tsis nug thiab nqa tus nqi ntawd twj ywm. Kuv tshawb nrhiav tsis tu ncua, nkaum kuv lub taubhau mus saib chaw saum kuv, thiab tus suab hu kev ceev faj qis ntawd ua rau kuv qaug zog thaum hnub twg tag. Kuv tsis pom ib tus neeg fuv tes ntawm sab tod ntawm ib chav tsev thiab zoo li kuv txias txias. Ib tus phooj ywg teem lus rau kuv saum ib theem nqes, thiab kuv poob ib nrab ntawm yam lawv hais thiab yuav tsum txiav txim siab seb nug dua los sis xam pom. Cov qhov tsaus nyob ntawm kuv puab tsaig raug nyeem tias yog kev txawj txwv. Txhua yam no me me. Ua ke lawv yog yam ntawm kev nyob nrog ib qho kev xiam oob khab uas tsis zoo li daim duab neeg nqa txog nws.

Thiab neeg nqa ib daim duab tiag tiag. Hais txog DeafBlind thiab feem ntau lub siab ncaj qha mus rau Helen Keller: kev ntsiag to tag nrho, kev tsaus ntuj tag nrho, ib txhais tes ntawm ib txhais tes. Qee tus DeafBlind nyob ze rau qhov ntawd, thiab lawv lub neej tsim nyog tau txais kev nkag siab raws li lawv tus kheej cov lus. Peb feem ntau tsis zoo li ntawd, thiab tib daim duab ntawd nres lwm tus tag nrho ntawm sab, nrog rau peb ntau tus uas tabtom mus kev, tsav tsheb, ua haujlwm, thiab teb email, nrog ib daim ntawm peb lub ntiaj teb ploj mus twj ywm.

Yam uas kuv thov

Kuv tsis thov kom leej twg pom yam kuv pom. Qhov ntawd tsis muaj peev xwm ua tau, thiab kuv kiag li kuj tsis pom tag nrho, vim kuv lub hlwb npog qhov sib txawv. Kuv thov ib yam yooj yim dua: thaum ib tus neeg qhia koj seb lawv lub cev ua haujlwm li cas, yuav tsum txais cov lus piav qhia ntawd ua cov ntaub ntawv tshiab, tsis yog ua ib qho kev thov uas yuav tsum raug sim saib raws li lawv zoo li cas. Yog kuv hais tias kuv yog DeafBlind, kuv tabtom qhia koj tias sab saum ntuj ntawm lub ntiaj teb tsis tso siab tau rau kuv thiab kuv tsis muaj suab nrov los pheej khaws. Yog kuv hais tias kuv nyiam email, kuv tabtom qhia koj seb kuv lub siab ua haujlwm zoo tshaj li li cas. Ob

qho tsis yog kev thov kev khuvxim, thiab ob qho tsis raug tawm tsam los ntawm qhov tseeb tias kuv tsav tsheb mus tau rau koj lub chaw ua haujlwm.

YOG KOJ UA HAUJLWM LOS SIS TEEM LUS NROG KUV

☐ Khaws koj txhais tes thiab ntsej muag nyob ntawm kuv qhov ntsia ncaj, thiab tsis txhob xav loj yog kuv tsis pom qee yam uas tshwm sim saum nws.

☐ Nkag mus rau hauv kuv kab ntsia es tsis txhob fuv tes saum toj.

☐ Sau ntawv rau kuv thaum koj xav tau kuv tej kev xav zoo tshaj, thiab muab lub sijhawm rau kuv teb.

Thiab yog koj ntsib ib tus neeg uas lawv qhov kev xiam oob khab tsis sib xws nrog daim duab hauv koj lub taubhau, xav txog qhov tias daim duab tej zaum yog yam tsis txaus. Kuv tus kheej yeej tsis txaus, ua ntej kuv kawm paub txog feem ntawm lub ntuj uas kuv tsis pom.

Cov chaw siv

1. Coussa, R. G., Basali, D., Maeda, A., DeBenedictis, M., & Traboulsi, E. I. (2019). Sector retinitis pigmentosa: Report of ten cases and a review of the literature. Molecular Vision, 25, 869–889. https://pmc.ncbi.nlm.nih.gov/articles/PMC6937219/
2. Helen Keller National Center Act, 29 U.S.C. § 1905(2) (definition of "individual who is deaf-blind"). https://www.law.cornell.edu/uscode/text/29/1905
3. Minnesota Rules, part 7410.2400, Vision. https://www.law.cornell.edu/regulations/minnesota/Minn-R-7410-2400

TIPS

Know something about a sign language AI system that the public should know? Send it to tips@novaracg.com. Every tip is read by me and kept confidential. If you work in the UK, writing to us is not by itself a protected disclosure under the Public Interest Disclosure Act 1998, so before you share employer information, check your options with Protect (protect-advice.org.uk), the free whistleblowing advice line.

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Yuav Hais Qhov Chaw Li Cas

Grizzle, H. M. (2026, October 8). The Sky I Don't See. Novara Consulting Group. https://www.novaracg.com/hmn/2026/10/08/the-sky-i-dont-see/