

Medications

Participant Name: _____

Doctor Name: _____

Participant Code: _____

Parent Name: _____

For Study Personnel Use, Only:

Coordinator Code: _____

Date: _____

1. Has anyone every discussed with you a genetic test to determine how your child metabolizes some medications? This would be referred to as PGx or pharmacogenomic testing.

- Yes No I'm not sure

2. Did you ever have PGx testing for your child, and if you did, were medications adjusted based on the results?

- No, I haven't had the PGx testing done
 Yes, I have had it done but have not done anything with the results
 Yes, I had the test done and worked with my doctor to adjust medications

3. Tell us what medications or treatments you/your child is currently taking for daily SEIZURE MANAGEMENT. If "Other", specify.

Select all that may apply, but ***do not*** select medications ONLY used for RESCUE in this question.

- | | | |
|---|--|---|
| <input type="checkbox"/> None | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Midazolam (Versed) | _____ |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Nitrazepam | _____ |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) | <input type="checkbox"/> Oxcarbazepine (Trileptal) | _____ |
| <input type="checkbox"/> CBZ | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Cannabadiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Phenytoin (Dilantin) | |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Potassium bromide KBr | |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Pregabalin (Lyrica) | |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Primidone (Mysoline) | |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Prozac | |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Quinidine | |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Rufinimide (Banzel) | |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Steroids | |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Stiripentol (DIACOMIT) | |
| <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Suthiame (Ospolat) | |
| <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Tiagabine (Gabitril) | |
| <input type="checkbox"/> Fenfluramine (Fintepline) | <input type="checkbox"/> Topiramate (Topomax, Trokendi) | |
| <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Vagus nerve stimulator | |
| | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) | |

4. Please select the efficacy level for the DAILY medications and treatments used for seizure management. If you did not try the drug, feel free to skip. But respond for each drug used for seizure management. *Please note: table continues on next page, alphabetically.*

	Very Effective	Somewhat Effective	Not Effective	Condition Worsened	Not Sure
Acetazolamide					
ACTH (Adrenocorticotropic Hormone)					
Ativan (Lorazepam)					
Brivaracetam (Briviact)					
Carbamazepine (Tegretol, Carbatrol)					
Coreg (carvedilol)					
Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana)					
Epidiolex					
Cenobamate (Xcopri)					
Clobazam (Onfi, Frisium)					
Clonazepam (Klonopin, Rivotril)					
Chlorazepate (Tranxene)					
Diazepam (Valium)					
Eslicarbazepine (Aptiom)					
Ethosuximide (Zarontin)					
Felbamate (Felbatol) FBM					
Fenfluramine (Fintepla)					
Gabapentin (Neurontin)					
Ketogenic diet					
Lacosamide (Vimpat)					
Lamotrigine (Lamictal)					
Levetiracetam (Keppra)					
Midazolam (Versed)					
Nitrazepam					

(Daily Seizure Medication Efficacy, cont.)

Very Effective **Somewhat Effective** **Not Effective** **Condition Worsened** **Not Sure**

Oxcarbazepine (Trileptal)					
Perampanel (Fycompa)					
Phenobarbital PB					
Phenytoin (Dilantin)					
Potassium bromide KBr					
Pregabalin (Lyrica)					
Primidone (Mysoline) Quinidine					
Quinidine					
Rufinamide (Banzel)					
Steroids					
Stiripentol (DIACOMIT)					
Suthiame (Ospolat)					
Tiagabine (Gabitril)					
Topiramate (Topamax, Trokendi)					
Vagus nerve stimulator					
Valproate, Valproic acid (Depakote, Depakene)					
Vigabatrin (Sabril)					
Zonisamide (Zonegran)					

If an OTHER medication, supplement or treatment was used for daily management of seizures, please list and indicate how well they worked.

5. Which medications or treatments have you/your child taken in the PAST for daily SEIZURE MANAGEMENT? If "Other", specify.

Only select those medications you have **stopped** using. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Does not apply (N/A) | <input type="checkbox"/> Fenfluramine (Fintepline) | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cannabadiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Nitrazepam | _____ |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Oxcarbazepine (Trileptal) | _____ |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Primidone (Mysoline) | |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Prozac | |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Quinidine | |
| <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |
| | <input type="checkbox"/> Steroids | |
| | <input type="checkbox"/> Stiripentol (DIACOMIT) | |
| | <input type="checkbox"/> Suthiame (Ospolat) | |

6. Which treatment did you stop using because it was not effective? Select for only treatment(s) you stopped using for this reason. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Fintepline) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabadiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | _____ |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

7. Which treatment did you stop using because it stopped working? Select only treatment(s) you stopped using ***for this reason***. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Finteplene) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | _____ |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

8. Which treatment did you stop using because there was a bad reaction/side effects?

Select only treatment(s) you stopped using ***for this reason***. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Finteplene) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | _____ |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

9. Which treatment did you stop using because it was replaced with another treatment?

Select only treatment(s) you stopped using ***for this reason***. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Fintepline) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobal, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

10. Which treatment did you stop using because the doctor discontinued for unknown reasons? Select only treatment(s) you stopped using ***for this reason***. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Fintepline) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobal, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

11. Which treatment did you stop using because the treatment became unavailable or hard to get? Select only treatment(s) you stopped using *for this reason*. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Finteplene) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | _____ |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

12. Which treatment did you stop using because the out of pocket cost? Select only treatment(s) you stopped using *for this reason*. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Finteplene) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabidiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | _____ |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

13. Which treatment did you stop using because the treatment increased seizures? Select only treatment(s) you stopped using ***for this reason***. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Finteplene) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabadiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

14. Which treatment did you stop using for other unknown reasons? Select only treatment(s) you stopped using ***for this reason***. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Ezogabine (Potiga, Retigibine) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Does not apply | <input type="checkbox"/> Felbamate (Felbatol) FBM | <input type="checkbox"/> Stiripentol (DIACOMIT) |
| <input type="checkbox"/> Acetazolamide | <input type="checkbox"/> Fenfluramine (Finteplene) | <input type="checkbox"/> Suthiame (Ospolat) |
| <input type="checkbox"/> ACTH (Cosyntropin, adrenocorticotrophic hormone) | <input type="checkbox"/> Gabapentin (Neurontin) GPT | <input type="checkbox"/> Tiagabine (Gabitril) |
| <input type="checkbox"/> Ativan (Lorazepam) | <input type="checkbox"/> Ketogenic diet | <input type="checkbox"/> Topiramate (Topomax, Trokendi) |
| <input type="checkbox"/> Brivaracetam (Briviact) | <input type="checkbox"/> Lacosamide (Vimpat) | <input type="checkbox"/> Vagus nerve stimulator |
| <input type="checkbox"/> Carbamazepine (Tegretol, Carbatrol) CBZ | <input type="checkbox"/> Lamotrigine (Lamictal) | <input type="checkbox"/> Valproate, Valproic acid (Depakote, Depakene) |
| <input type="checkbox"/> Coreg (carvedilol) | <input type="checkbox"/> Levetiracetam (Keppra) LEV | <input type="checkbox"/> Vigabatrin (Sabril)GVG |
| <input type="checkbox"/> Cannabadiol CBD without THC (not Epidiolex brand, medical marijuana) | <input type="checkbox"/> Midazolam (Versed) | <input type="checkbox"/> Zonisamide (Zonegram) |
| <input type="checkbox"/> CBD with THC combination (Sativex) | <input type="checkbox"/> Nitrazepam | <input type="checkbox"/> Zyprexa |
| <input type="checkbox"/> Epidiolex | <input type="checkbox"/> Oxcarbazepine (Trileptal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Cenobamate (Xcopri) | <input type="checkbox"/> Perampanel (Fycompa) | _____ |
| <input type="checkbox"/> Clobazam (Onfi, Frisium)CLB | <input type="checkbox"/> Phenobarbital PB | _____ |
| <input type="checkbox"/> Clonazepam (Klonopin, Rivotril) | <input type="checkbox"/> Phenytoin (Dilantin) | _____ |
| <input type="checkbox"/> Chlorazepate (Tranxene)CZP | <input type="checkbox"/> Potassium bromide KBr | _____ |
| <input type="checkbox"/> Diazepam (Benzodiazepine) | <input type="checkbox"/> Pregabalin (Lyrica) | _____ |
| <input type="checkbox"/> Eslicarbazepine (Aptiom) | <input type="checkbox"/> Primidone (Mysoline) | _____ |
| <input type="checkbox"/> Ethosuximide (Zarontin) | <input type="checkbox"/> Prozac | |
| | <input type="checkbox"/> Quinidine | |
| | <input type="checkbox"/> Retigabine (Trobalt, Potiga) | |
| | <input type="checkbox"/> Rufinimide (Banzel) | |

15. What medication *or* combination of medications worked best to reduce seizures on a daily or interval routine? (Even if it stopped working later) If none, skip.

16. Was there any medication *or* combination of medications that increased seizures? If yes, name the medication(s). If none, skip.

17. Were there any medications that worked temporarily (“honeymoon period”) and then stopped working? If so, list them here. If none, skip.

18. Have you ever had to use any rescue medications when seizures are clustered or too many to count-- and if so, how often? Check all that apply.

- Does not apply
- No, have not had to use rescue meds
- Yes, but only once
- Yes, use daily
- Yes, use more than once per week
- Yes, use every other month
- Yes, have to use 2-4 times per year
- Yes, use once per year

19. Please select the efficacy level for the RESCUE or EMERGENCY medications and treatments used. If you did not use the medication for rescue or emergency, leave it blank.

Very Effective
Somewhat Effective
Not Effective
Condition Worsened
Not Sure

Acetazolamide (Diamox)					
Birvaractam (Briviact)					
Bromide					
Carbamazepine (Tegretol)					
CBD/medical marijuana (not Epidiolex)					
Clobazam (Onfi, Frisium)					
Clonazepam (Klonopin) - Oral					
Diazepam, Valtoco - Intranasal					
Diazepam - Rectal					
Ethosuximide (Zarontin)					
Felbamate (Felbatol, Taloxa)					
Fosphenytoin (Cerebyx)					
Fosphenytoin - IV administered					
Gabapentin (Neurontin, Gralise)					
Lamotrigine (Lamictal)					
Levetiracetam (Keppra)					
Levetiracetam (Keppra) - IV administered					
Lorazepam (Ativan) - IV administered					
Midazolam (Versed) or Selzalam - Intramuscular (IM)					
Midazolam Liquid - Oral Buccal					
Midazolam - IV administered					
Naylizam - Intranasal					
Oxcarbazepine (Trileptal)					
Phenobarbital (Phenobarbitone, Gardenal)					
Valproic Acid - IV administered					

20. If you used any other medications for emergency or rescue, list them below. *For each*, circle how well they worked: *Very Effective (VE)*, *Somewhat Effective (SE)*, *Not Effective (NE)*, *Condition Worsened (CW)* or *Not Sure (NS)*. If you did not use any other rescue/emergency medications, leave blank.

_____	VE	SE	NE	CW	NS
_____	VE	SE	NE	CW	NS
_____	VE	SE	NE	CW	NS
_____	VE	SE	NE	CW	NS

21. Some parents report that their child has fewer seizures when they are sick. Do you observe fewer seizures when your child has a minor infection or fever and they are NOT taking an antibiotic?

- Yes
 No
 Not sure
 Does not apply

22. Do you notice a change in seizures when your child is taking an antibiotic? If you did not use the antibiotic, feel free to skip. But respond for each antibiotic used. *Please note: table continues on next page, alphabetically.*

	Not Sure	More Seizures	Fewer Seizures	No Change
Amoxicillin				
Amoxicillin clavulanate (Augmentin)				
Azithromycin				
Ceftriaxone				
Cefuroxime				
Cephalexin				
Ciprofloxacin				
Clarithromycin				
Clindamycin				
Erythromycin				
Ertapenem				

(Antibiotic Seizure Impact, cont.)

	Not Sure	More Seizures	Fewer Seizures	No Change
Geantamicin				
Imipenem				
Levofloxacin				
Meropenem				
Metronidazole				
Moxifloxacin				
Neomycin				
Penicillin				
Streptomycin				
Tobramycin				

23. What does your child take for gut dysmotility or issues with constipation and diarrhea?

- | | |
|--|---|
| <input type="checkbox"/> Does not apply to my child | <input type="checkbox"/> Prebiotics and/or probiotics |
| <input type="checkbox"/> None | <input type="checkbox"/> Prune juice |
| <input type="checkbox"/> Aprepitant | <input type="checkbox"/> Relamorelin |
| <input type="checkbox"/> Bethanechol | <input type="checkbox"/> Resotran |
| <input type="checkbox"/> Botulinum toxin injection | <input type="checkbox"/> Sorbitol |
| <input type="checkbox"/> Cisapride | <input type="checkbox"/> Senna |
| <input type="checkbox"/> Citalopram | <input type="checkbox"/> Suppositories |
| <input type="checkbox"/> Domperidone | <input type="checkbox"/> Zantac |
| <input type="checkbox"/> Felcisetrag | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Flagyl | _____ |
| <input type="checkbox"/> Glycerin | _____ |
| <input type="checkbox"/> Lactulose (Constulose, Enulose, Generlac, Kristalose) | _____ |
| <input type="checkbox"/> Lansoprazole | _____ |
| <input type="checkbox"/> Loperamide | |
| <input type="checkbox"/> Magnesium citrate (Citroma) | |
| <input type="checkbox"/> Magnesium hydroxide (Milk of Magnesia) | |
| <input type="checkbox"/> Metoclopramide | |
| <input type="checkbox"/> Neostigmine | |
| <input type="checkbox"/> Polyethylene glycol (MiraLAX, Dulcolax Balance) | |

24. What does your child take to manage reflux?

- | | |
|--|--|
| <input type="checkbox"/> Not applicable (child does not experience reflux) | <input type="checkbox"/> Omeprazole (Prilosec) |
| <input type="checkbox"/> None | <input type="checkbox"/> Pantoprazole (Protonix) |
| <input type="checkbox"/> Cimetidine (Tagamet) | <input type="checkbox"/> Rabeprazole (Aciphex) |
| <input type="checkbox"/> Dexlansoprazole (Dexilant) | <input type="checkbox"/> Someprazole (Nexium) |
| <input type="checkbox"/> Famotidine (Pepcid) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Lansoprazole (Prevacid) | _____ |
| <input type="checkbox"/> Maalox | _____ |
| <input type="checkbox"/> Mylanta | |

25. What does your child take to address sleep issues?

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Not applicable (child does not experience sleep issues) | <input type="checkbox"/> Trazodone |
| <input type="checkbox"/> None | <input type="checkbox"/> Triazolam |
| <input type="checkbox"/> Benadryl (Diphenhydramine) | <input type="checkbox"/> Zaleplon |
| <input type="checkbox"/> Estazolam | <input type="checkbox"/> Zolpidem |
| <input type="checkbox"/> Gabapentin | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Hydroxyzine | _____ |
| <input type="checkbox"/> Melatonin | _____ |
| <input type="checkbox"/> Suvorexant | _____ |

26. What does your child currently take to address HIGH muscle tone (or “spasticity”)?

- | | |
|--|--|
| <input type="checkbox"/> Not applicable (child does not experience sleep issues) | <input type="checkbox"/> Diazepam |
| <input type="checkbox"/> None | <input type="checkbox"/> Tizanidine (Zanaflex) |
| <input type="checkbox"/> Baclofen (Lioresal) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Clonazepam | _____ |
| <input type="checkbox"/> Dantrolene sodium (Dantrium) | _____ |

27. What do you currently take to address secretions?

- | | |
|---|--|
| <input type="checkbox"/> Not applicable (child does not experience secretion) | <input type="checkbox"/> Trihexyphenidyl (Benzhexol) |
| <input type="checkbox"/> None | <input type="checkbox"/> Glycopyrrolate |
| <input type="checkbox"/> Atropine | <input type="checkbox"/> Glycopyrronium bromide |
| <input type="checkbox"/> Benztropine | <input type="checkbox"/> Scopolamine (Hyoscine) |
| <input type="checkbox"/> Botox | <input type="checkbox"/> Other: _____ |
| | _____ |
| | _____ |
| | _____ |

28. What do you currently take to address or prevent respiratory illnesses, pulmonary or breathing issues?

- | | |
|---|---|
| <input type="checkbox"/> Not applicable | <input type="checkbox"/> Nedocromil Sodium (Tilade) |
| <input type="checkbox"/> None | <input type="checkbox"/> Pirbuterol (Maxair) |
| <input type="checkbox"/> Albuterol (Proventil, Ventolin) | <input type="checkbox"/> Prednisone Salmeterol (Serevent) |
| <input type="checkbox"/> Antibiotics | <input type="checkbox"/> Terbutaline (Brethaire) |
| <input type="checkbox"/> Bitolterol (Tornalate) | <input type="checkbox"/> Triamcinolone (Azmacort) |
| <input type="checkbox"/> Beclomethasone (Beclivent, Vanceril) | <input type="checkbox"/> Warfarin Sodium (Coumadin) |
| <input type="checkbox"/> Budesonide (Pulmicort) | <input type="checkbox"/> Xopenex (levalbuterol) |
| <input type="checkbox"/> Cromolyn Sodium (Intal) | <input type="checkbox"/> Zafirlukast (Accolate) |
| <input type="checkbox"/> Fluticasone (Flovent) | <input type="checkbox"/> Zileuton (Zyflo) |
| <input type="checkbox"/> Flunisolide (AeroBid) | <input type="checkbox"/> Omalizumab (Xolair) |
| <input type="checkbox"/> Formoterol (Foradil) | <input type="checkbox"/> Brethaire (terbutaline) |
| <input type="checkbox"/> Ipratropium (Atrovent) | <input type="checkbox"/> Maxair (pirbuterol) |
| <input type="checkbox"/> Levalbuterol (Xopenex) | <input type="checkbox"/> Metaprel (metaproterenol) |
| <input type="checkbox"/> Metaproterenol (Alupent, Metaprel) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Methylprednisolone (Medrol) | _____ |
| <input type="checkbox"/> Montelukast (Singulair) | _____ |
| | _____ |

29. What do you currently take to address pain?

- | | |
|---|---------------------------------------|
| <input type="checkbox"/> Not applicable (child does not experience pain requiring advanced treatment) | <input type="checkbox"/> Ibuprofen |
| <input type="checkbox"/> None | <input type="checkbox"/> Naproxen |
| <input type="checkbox"/> Acetaminophen (Tylenol, Tempra, Panadol, Aspirin-free Paracetamol) | <input type="checkbox"/> Opioid |
| <input type="checkbox"/> FeverAll (suppository) | <input type="checkbox"/> Paracetamol |
| <input type="checkbox"/> Gabapentin | <input type="checkbox"/> Other: _____ |
| | _____ |
| | _____ |
| | _____ |

30. What does your child take for to maintain bone health?

- | | |
|--|--|
| <input type="checkbox"/> Not applicable (child does not experience bone health issues) | <input type="checkbox"/> Vitamin D |
| <input type="checkbox"/> None | <input type="checkbox"/> Zoledronic (Zometa and Reclast) through an IV |
| <input type="checkbox"/> Alendronate (Fosamax) | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Pamidronate (Aredia) through an IV | _____ |
| | _____ |
| | _____ |

31. What do you currently take to address alertness?

- | | |
|--|--|
| <input type="checkbox"/> Not applicable (child does not experience alertness/attention issues) | <input type="checkbox"/> Dynavel XR |
| <input type="checkbox"/> None | <input type="checkbox"/> Focalin |
| <input type="checkbox"/> Adzenys XR | <input type="checkbox"/> Jornay PM |
| <input type="checkbox"/> Adderall | <input type="checkbox"/> Quillivant XR |
| <input type="checkbox"/> Concerta | <input type="checkbox"/> Ritalin |
| <input type="checkbox"/> Daytrana | <input type="checkbox"/> Vyvanse |
| | <input type="checkbox"/> Other: _____ |
| | _____ |
| | _____ |
| | _____ |

32. What do you currently take to address mood?

- | | |
|--|---|
| <input type="checkbox"/> Not applicable (child does not experience mood dysregulation) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> None | <input type="checkbox"/> Lithium |
| <input type="checkbox"/> Aripiprazole (Abilify) | <input type="checkbox"/> Lurasidone (Latuda) |
| <input type="checkbox"/> Bupropion (Wellbutrin) | <input type="checkbox"/> Nortriptyline (Pamelor) |
| <input type="checkbox"/> Carbamazepine (Carbatrol, Epiol, Equetro, Tegretol) | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> Divalproex sodium (Depakote) | <input type="checkbox"/> Risperidone (Risperdal) |
| <input type="checkbox"/> Fluoxetine (Prozac) | <input type="checkbox"/> Valproic acid (Depakene) |
| <input type="checkbox"/> Fluvoxamine | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Imipramine (Tofranil) | _____ |
| | _____ |
| | _____ |

33. What do you currently take to address heart issues?

- | | |
|--|---|
| <input type="checkbox"/> Not applicable (child does not experience heart issues) | <input type="checkbox"/> Furosemide (Lasix) |
| <input type="checkbox"/> None | <input type="checkbox"/> Ivabradine |
| <input type="checkbox"/> Amiodarone | <input type="checkbox"/> Lanoxin |
| <input type="checkbox"/> Carvedilol | <input type="checkbox"/> Sotalol |
| <input type="checkbox"/> Cialis / Levitra / Viagra | <input type="checkbox"/> Valsartan (Diovan) |
| <input type="checkbox"/> Dronedarone | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Flecainide | _____ |
| | _____ |
| | _____ |

34. What do you currently take to treat infections or address immunodeficiency?

- | | |
|---|--|
| <input type="checkbox"/> Not applicable (child does not experience chronic infections or immunodeficiency issues) | <input type="checkbox"/> Synathcin |
| <input type="checkbox"/> None | <input type="checkbox"/> Vigabatrin/Sabril |
| <input type="checkbox"/> ACTH/Acthar | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Antibiotics | _____ |
| <input type="checkbox"/> Intravenous immunoglobulin (IVIg) | _____ |
| <input type="checkbox"/> Oral steroids (e.g. prednisone, prednisolone) | |

35. What does your child currently take to address bladder, liver, or urinary issues?

- | | |
|---|--|
| <input type="checkbox"/> Not applicable (child does not experience bladder, liver, or urinary issues) | <input type="checkbox"/> Trimethoprim/sulfamethoxazole or nitrofurantoin |
| <input type="checkbox"/> None | <input type="checkbox"/> Silodosin |
| <input type="checkbox"/> Prazosin | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Terazosin | _____ |
| | _____ |

36. What does your child currently take to address dysautonomia issues? (Ex. sweating, cold, rapid or slow heart rate, dilated or small pupils, etc.)

If responding "Other", please include any unlisted medications, supplements, and/or nutraceuticals.

- | | |
|--|--|
| <input type="checkbox"/> Not applicable (child does not experience dysautonomia) | <input type="checkbox"/> Gabapentin |
| <input type="checkbox"/> None | <input type="checkbox"/> Midodrine |
| <input type="checkbox"/> Amantadine | <input type="checkbox"/> Clonidine/Dexmedetomidine |
| <input type="checkbox"/> Baclofen | <input type="checkbox"/> SSRI serotonergic medications |
| <input type="checkbox"/> Carbidopa/Levodopa/Sinemet | <input type="checkbox"/> Stimulants, Methylphenidate, Concerta, Daytrana patch |
| <input type="checkbox"/> Fludrocortisone/mineralocorticoid | <input type="checkbox"/> Other: _____ |
| | _____ |
| | _____ |
| | _____ |
| | _____ |
| | _____ |
| | _____ |

37. List any other medications you take that were not already mentioned. If you know what they are for, include what they are used for. If there are no additional medications, leave blank.

Other Medication Name	Use