

What we want to see in the future

Community

Friends

New research

Connections

Learning

Connection

Sharing

GLUT1 Family

Sharing experiences

To get more information

Gathering with families

Friendship

Caring for Mia

Learn new things

Glenna

My daughter

New diagnosis

My wife

Daughter

Work

Ketogenic

Dietitians

Flash talk

Research opportunities

Support community

Research

Support

Knowledge

Love

G1D friends

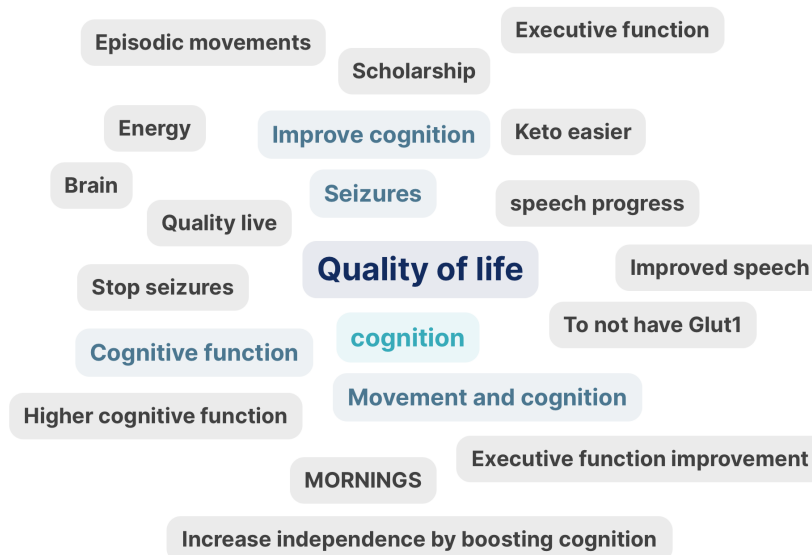
Education for Roman

Sciences



Imagine we could solve one challenge for people living with GLUT1 Deficiency - what would it be?

Wordcloud Poll ☒ 40 responses  37 participants



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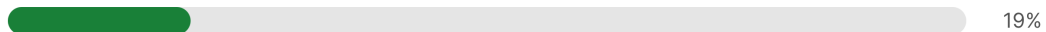
When you think about GLUT1DS, what matters most to patients and families?

Multiple Choice Poll ☒ 74 votes  74 participants

seizure freedom - 1 vote



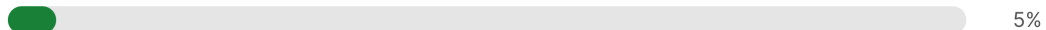
independence - 14 votes



learning and school - 3 votes



social relationships - 4 votes



quality of life - 52 votes



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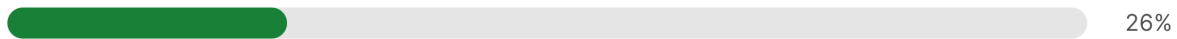
What do you think is the greatest long-term challenge for people with GLUT1DS?

Multiple Choice Poll 72 votes 72 participants

seizures - 1 vote



movement disorders - 19 votes



cognitive difficulties - 45 votes



behavioral and emotional problems - 7 votes



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cognitive



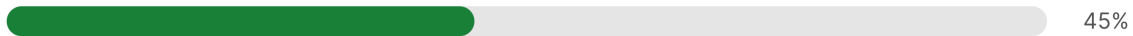
Rate your loved one's cognitive challenges:

Multiple Choice Poll 71 votes 71 participants

none - 1 vote



mild - able to do most things peers do with support - 32 votes



moderate - unable to do many things peers do = adaptations - 25 votes



severe - substantial impact and support needed - 13 votes



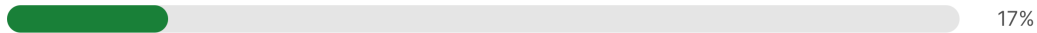
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Which factor do you think has the greatest impact on cognitive outcomes in GLUT1DS?

Multiple Choice Poll ☒ 77 votes  77 participants

type of mutation - 13 votes



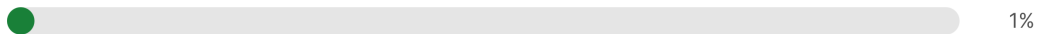
seizure control - 3 votes



age at KDT initiation - 52 votes



duration of KDT - 1 vote



I don't know - 8 votes



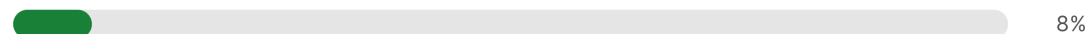
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Which cognitive domain do you think is most affected in GLUT1DS?

Multiple Choice Poll ☒ 77 votes  77 participants

attention - 6 votes



language - 19 votes



memory - 5 votes



executive function - 46 votes



visuospatial abilities - 1 vote



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movement



Rate your loved one's movement challenges:

Multiple Choice Poll 62 votes 62 participants

none - 3 votes



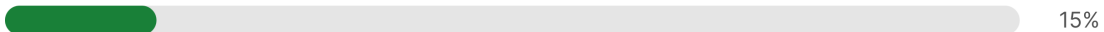
mild - some difficulties but able to complete most daily activities - 34 votes



moderate - activity, mobility, participation affected, supports needed - 16 votes



severe - significant mobility challenges, substantial support needed - 9 votes

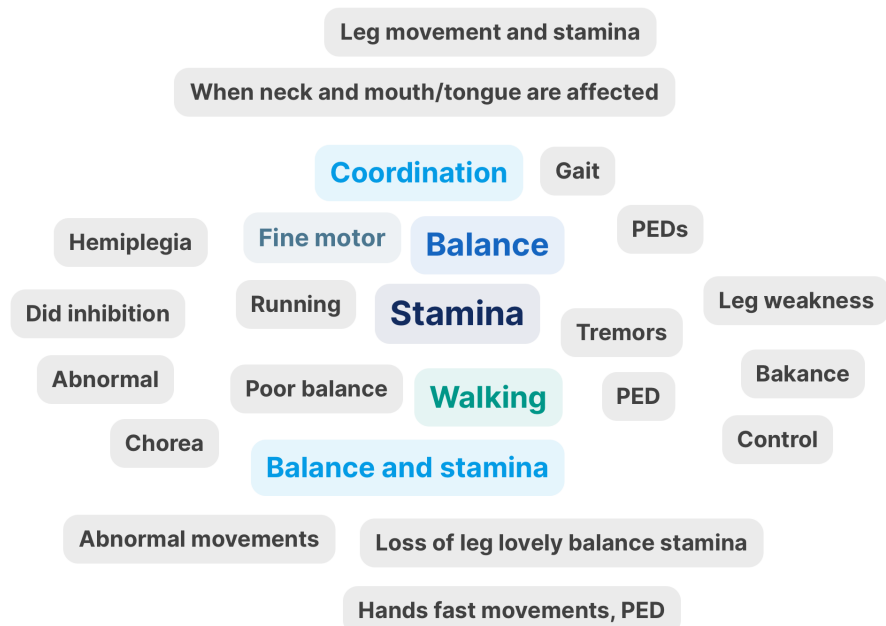


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Which types of movement related symptoms are the most difficult or uncomfortable?

Wordcloud Poll 56 responses 51 participants



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Do any of these factors affect walking for you? (select up to 3)

Multiple Choice Poll 63 votes 63 participants

walking speed not fast enough - 26 votes



fatigues quickly, low endurance - 51 votes



pain or discomfort - 5 votes



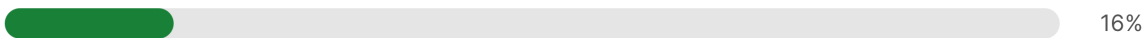
poor balance or frequent falls - 27 votes



worry about triggering an episode of involuntary movements - 18 votes



something else or other - 10 votes



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movement EXPERIENCES

1 = unable to do anything 10 = excellent, able to do about anything without limitations



Think of the number between 1-10 that represents functional level at its BEST



Think of the number between 1-10 that represents functional level at its WORST

subtract the low number from the high number

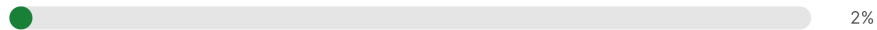
0 = functional level is always consistent 9 = functional level is highly variable



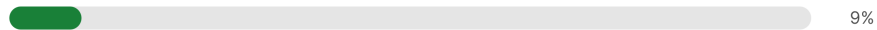
What is your functional number?

Multiple Choice Poll 58 votes 58 participants

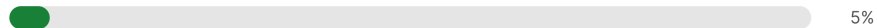
0 - 1 vote



1 - 5 votes



2 - 3 votes



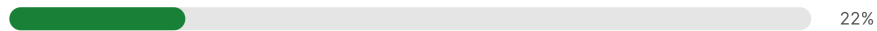
3 - 5 votes



4 - 12 votes



5 - 13 votes



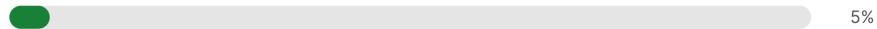
6 - 6 votes



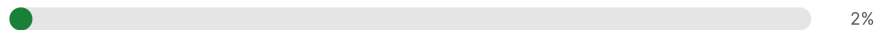
7 - 9 votes



8 - 3 votes



9 - 1 vote





Which strategies are most helpful for preventing or managing episodic movement symptoms? (select up to 3)

Multiple Choice Poll 63 votes 63 participants

time meals/food intake - 42 votes



carefully plan how much you do and when to do it - 35 votes



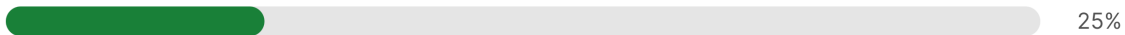
if symptoms occur, stop and rest - 35 votes



physical therapy - 7 votes



physics supports (braces, walker, wheelchair, other devices) - 16 votes



medications - 9 votes



none - 1 vote



something else or other - 9 votes



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seizures



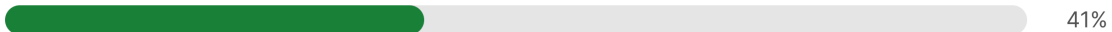
Rate the impact of seizures for your loved one:

Multiple Choice Poll  51 votes  51 participants

none-no seizures - 12 votes



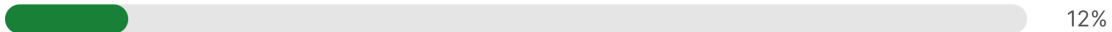
mild - infrequent and have little impact on daily life - 21 votes



moderate - require regular management and sometimes interfere with everyday activities - 12 votes



severe - major daily concern, affecting safety, participation, and quality of life - 6 votes



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Which treatments have you found beneficial for improving seizure control or lessening severity?

Open text poll  50 responses  42 participants

- Valproic acid gave us total control
- Primidone plus KD
- Ethosuximide
- Keto diet mct
- Great sleep
- C7
- Possibly MAD
- KTD & Diamox
- Keppra
- Mct
- Rest keto diet and taking care of myself
- Ketogenic diet plus meds
- Berberine
- Keto diet only
- Ketogenic Diet
- Briviact
- Keto diet, C7
- Regular feeding
- Diamox and KD together
- Rest
- Diet
- Hemp oil
- Keto and lifestyle changes to diet, sleep, elimination of chemicals
- Keppra
- Keto +Zonisamide
- Meds briviact
- Classical KDT
- Diamox and Keto diet
- Mct oil
- Keto
- Diet, rest.
- Keto diet
- Still searching
- Diazoxide

speech and language



Rate your loved one's speech & language challenges:

Multiple Choice Poll

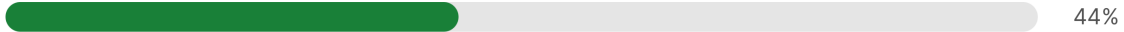
✓ 64 votes

👤 64 participants

none - 7 votes



mild - some difficulties but able to express needs and converse - 28 votes



moderate - communication regularly affected, supports needed - 17 votes



severe - significant difficulty, communication very limited - 12 votes



slido



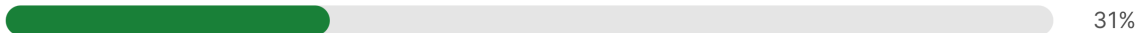
Is speech production easier or clearer in pronunciation when the child has involuntary compared to voluntary speech?

Multiple Choice Poll

✓ 58 votes

👤 58 participants

involuntary speech is easier or clearer - 18 votes



voluntary speech is easier or clearer - 12 votes



no difference - 28 votes





Does speech production ease or clarity change over a day or days, and if so, why?

Open text poll  55 responses  51 participants

- Some days are better than others perhaps energy level matters
- younger age louder
- Stress, migraines, fatigue
- Before the meal, after streets
- Day to day
- I see a lot of shutting down and unwillingness to speak at certain times and I can't pinpoint, but I think over excitement, being upset, tiredness, illness has an impact
- Movement episodes in tongue affect her speech
- When fatigued, when experiencing movement disorder
- Movement sometimes affects tongue
- After tired fatigue and energy level
- Worse at night, speech slows and she sounds drunk
- depending on diet compliance and level
- Of fatigue
- Worse when tired.
- Slower on bad days; more of processing delay.
- Worse with movements
- Fatigue makes speech worsen
- Speech is generally the same, although sometimes doesn't really talk at all and other times talks a lot!
- Maybe worse when tired. Otherwise consistent struggles.
- When he is nervous it gets worse
- Yes ... stress may, tired , illness
- Before meals, when tired or overwhelmed is definitely affected.
- Better after socialization with others
- Worse with fatigue
- Morning better
- Slower rate of speech on bad days.
- Clarity decreases with fatigue
- PEDs affect speech
- Later in day worse
- Somewhat with fatigue
- We notice speech changes only with hemiplegic migraines
- Worse in the morning
- Speech worsens when excited and over stimulated.
- Not much fluctuation
- Stress, emotional distress, exhaustion
- Variable.
- Better post activity
- Better after a meal. Worse at night.
- During the menstrual cycle
- After tired it gets worse
- Morning is better.
- Worse when ketones low
- No differences
- Better in am
- No change



Are speech production changes also time-linked to other issues?

Open text poll  52 responses  49 participants

- When full charged speech much better... anything that takes energy away loosens the mouth muscles , thinking.
- Def see issues while having movement. Affects tongue and mouth movement
- Very difficult formulating his ideas into speech. "Thinking" slows his speech considerably
- 1 patient had movement issue impacting mouth
- I can't tell the difference between an absence seizure or voice change later in the day
- With any type of episode, speech will get slower and overall worsen
- when emotional worse
- Yes. Seizures and fatigue affect speech. Seizures can result in no ability to speak after.
- No real difference with movement issues. Is worse on low days
- Low ketones
- Yes with migraine episode
- Low days
- Fatigue
- Yes during low days
- Movement episode, seizure, stress
- With energy level
- Worse at low times
- Worse when tired
- Depends on severity or frequency of seizure episodes
- Yes - when motor issue is happening - also affects chewing food
- If movement, speech, if any, is very, very slurred.
- PEDs can greatly affect speech
- Not obvious
- Worse when ketones low
- Definitely issues during fatigue or seizures.
- When tired, especially after physical exertion speech is worse.
- Occasionally movement episodes affect tongue and speech
- Yes
- Energy levels, seizures, etc
- Fatigue and movement episode
- On low days she has difficulty speaking
- Only with hemiplegic migraines
- Yes, can be related to movement
- Yes with movement episodes in mouth or tongue
- No difference
- Yes, speech is degraded when having bad days.
- Worse on low days.
- I don't see correlation with movement disorders
- Nope
- Not really
- Worse on low days
- No
- No change



Is there more difficulty pronouncing consonants compared to vowels?

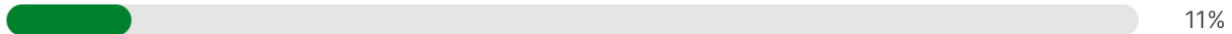
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Multiple Choice Poll ☒ 54 votes  54 participants

more difficulty pronouncing consonants - 30 votes



more difficulty pronouncing vowels - 6 votes



no difference - 18 votes



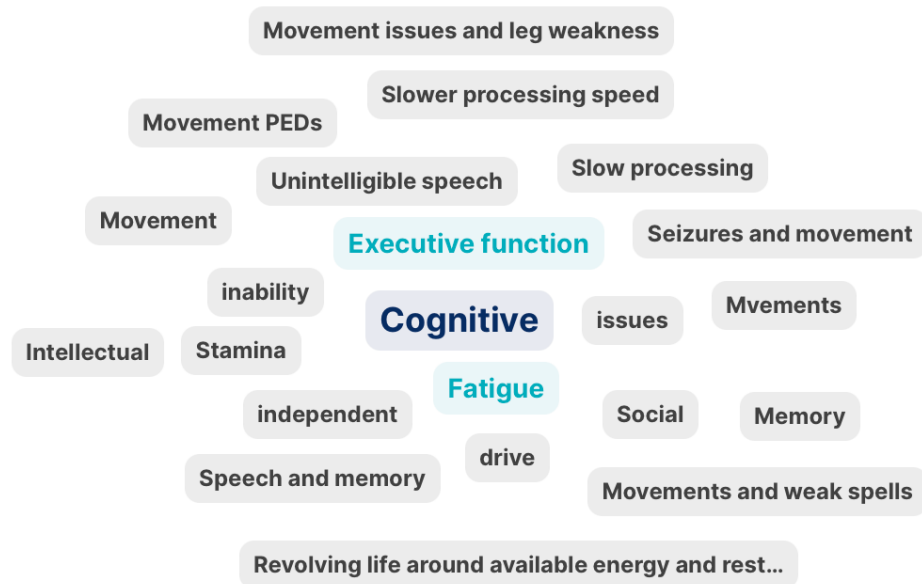
adult experiences



Which symptoms seem to have the most impact on quality of life in adulthood?

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Wordcloud Poll ☒ 30 responses  26 participants





How have your adult experiences with symptoms or treatments changed compared to those in childhood?

Open text poll  29 responses  25 participants

- Finally have seizures controlled
- anxiety, depression
- I was diagnosed as adulthood
- Less energy
- Less strict for diet
- Speech worsened
- Being compliant with better food choices
- In childhood I had more leg problems and in adulthood I have more overall movements
- Seizures decreased
- Noncompliance
- Developed movement issues
- Slight improvement with diet
- More hormonal related issues in adulthood
- Diet change from classic 3:1 KTD to MAD
- More movement
- Issues around puberty
- More movements, no seizures. Stopped seizure meds.
- Compliance. Movement episodes increased
- Movement
- Movements worsened
- They haven't changed - continuing keto and medication
- Came off all medical diets
- More stability
- More fatigue, less energy
- Doctors don't understand!
- I was diagnosed and started diet in adulthood
- More movement issues



Are there any strategies you've found to help with symptoms at this stage?

Open text poll  30 responses  26 participants

- Needed to add medications
- Sleep more
- Social interaction
- Medication and exercise
- PT, working with a trainer 2xs a week
- Running
- Slowing down to work at my pace
- Exercise often. Generates endorphins
- Diet and medication
- Equestrian therapy
- Mental health med
- Sleep
- More snacks as needed
- G tube
- Weak spells seem to pass quicker with coke or chocolate milk
- Frequent naps
- Sleep, breathing practices
- Snack & oil boosts
- Changing meds
- Snacks
- Speech therapy
- Routine life
- Routine
- Exercise often
- Pt and ot
- Exercise
- Finding joy

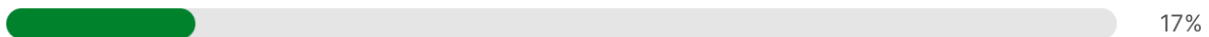


Have you transitioned to adult neurology or diet services yet?

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Multiple Choice Poll  29 votes  29 participants

no - 5 votes



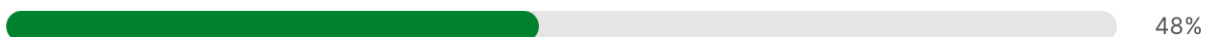
no but in planning stages - 6 votes



currently transitioning - 4 votes



yes - 14 votes





Rate your loved one's social challenges:

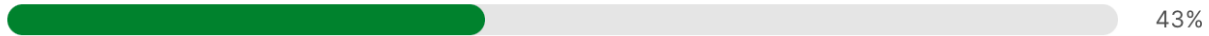
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Multiple Choice Poll ☒ 44 votes  44 participants

none - no significant challenges - 2 votes



mild - some difficulties but generally able to interact and participate socially - 19 votes



moderate - friendships, communication, or participation affected, support sometimes needed - 17 votes



severe - interactions and relationships greatly limited, substantial support needed - 6 votes



What seem to be the biggest social challenges for your loved ones?

Open text poll ☒ 46 responses  42 participants

- Nothing in common
- Finding groups to interact with
- Maintaining meaningful friendships
- Not assuming you know what they need- ask them
- Anxiety and being understood
- Initiating activities with friends and maintaining friendships outside of structured settings
- Maintaining friends with peers
- Knowing when to stop or the moment has had its time
- Initiated social time with friends
- Finding a boyfriend on dating apps.
- Holding a conversation
- Confidence
- Social norms and also initiating social experiences
- Difficulty communicating
- Going into an new situation
- Immature for age
- Speech
- Reciprocal communication
- Inability to talk
- Understanding social cues
- Maintaining friendships
- Communication
- Frustration
- Eye contact and communication
- Difficult for people to understand what's being said
- Getting him to open up around others in social settings. Confidence
- Frustrated easily if done way
- Shy when around new people - really opens up and can be himself once he gets to know someone
- Understand social situations
- Anxiety in new or busy environments
- Social skill
- Initiating conversation and engaging in reciprocal conversation
- Keeping a conversation going or understanding the dynamics of conversations
- Shyness
- Social norms
- Being in a group setting
- Adult relationships without the opportunity to practice as a teen
- Friends from younger years have moved on



Do you have strategies or supports that you have found helpful in this area/

Open text poll  31 responses  30 participants

- Volunteering
- Loop noise reducing ear plugs for reducing anxiety and overstimulation
- A good group of friends and family to talk to about my problems.
- Finding what causes anxiety so we can prepare
- Playing Scrabble, following interests and engaging around them
- Texting talking points to my child's phone so he can reference
- Setting a plan and talking about it.
- Community activities
- Finding friends
- Modeling, thinking out loud
- Front load and meet them where they are at
- We try to suggest topics find common interests.
- Family support.
- Encouragement and support
- Enrolling in a structured activity
- Plan ahead and always have exit strategy
- Overall support for their interests
- Modeling interacting with others
- Athletic community
- His aide at school would help him to engage with his perrs
- Backing off and let things happen naturally
- Preparing for potential conversations
- Loves elderly!
- Having a sibling for social support
- Special Olympics
- Practice conversation before event
- Finding a buddy
- Sibling support
- Set a plan

ketogenic diet



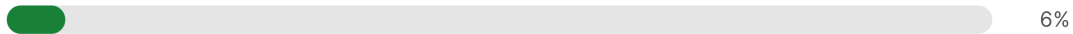
Rate your loved one's experiences with KDT:

Multiple Choice Poll ☒ 52 votes  52 participants

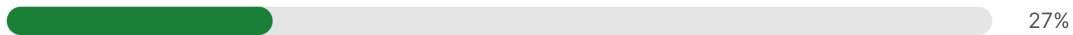
have not tried or unable to use KDT - 6 votes



mildly effective overall - 3 votes



moderately effective overall - 14 votes



extremely effective overall - 29 votes

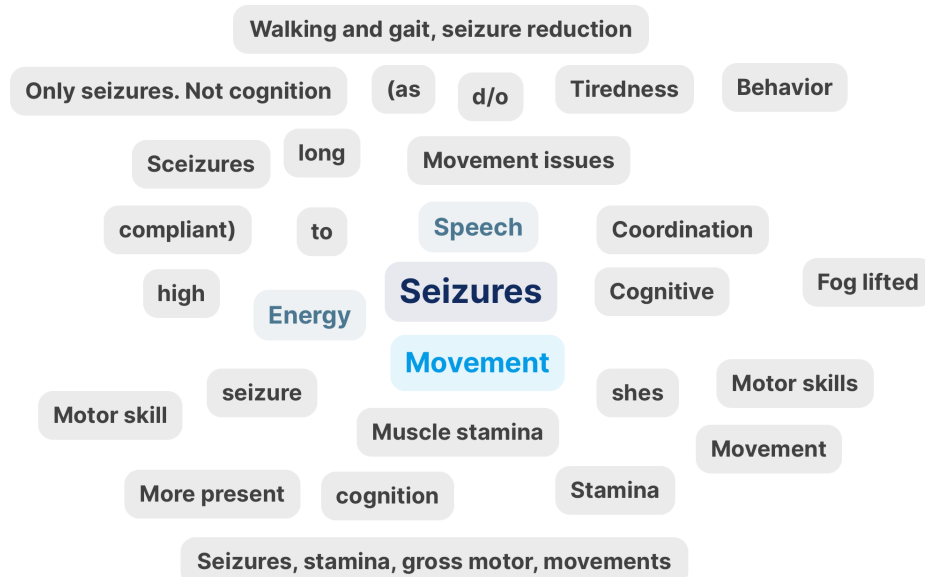


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Which symptoms have responded favorably to KDT?

Wordcloud Poll ☒ 63 responses  43 participants



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takeaways: clinical sessions



Please share a takeaway or highlight from today's sessions:

Open text poll



39 responses



35 participants

- Symptoms change over time, seizures change. Be flexible with treatment
- cornstarch
- Ketogenic diet is the best treatment
- Personalized KD
- Keto diet 5 different types and options
- We are surrounded by amazing other people and not alone!
- Customized keto
- Fucosa
- Fucose is very promising and we need more participants
- Patient stories
- Information about new clinical trials was encouraging
- Puberty info
- Patient presentations of young adults give hope
- Dr Pasquale & Keto team
- Love the family testimonials
- Stay creative
- There are more treatment options for our patients. More hope for the community
- Lots of interesting new research currently in progress
- Multiple treatment avenues
- Ketogenic diet is gold standard
- Promising new ideas
- Look into Fucose trail
- There are more options for potential treatments in progress.
- Becky Olson info
- The power of the keto diet as the one treatment for GLUT 1 DS
- Puberty changes
- Treatment options
- Diamox
- Hopw
- New trails and patient stories
- school resources
- Talking one on one with an expert
- Dr Pascual presentation
- fucose
- Family stories, patient stories
- Fucose trial
- Look into Fucose

takeaways: family sessions



What are some takeaways and highlights of the Asheville Summit for you?

Open text poll  54 responses  42 participants

- Community ❤️ SO thankful to share this journey!
- Connection
- Great collaborativecommunity
- A highlight is always meeting the families who are dealing with similar situations
- Other treatments other than keto
- fucose
- Not to focus completely on the diet
- Gratitude
- Making friends
- New treatment ideas
- Meeting experts in Glut1
- Support from others
- We are not the only ones!
- Amazing!!!
- Lots of interesting new treatments on the horizon
- Loved the patient and family presentations
- New friends that understand
- There is so much HOPE!
- Special needs trust
- Emerging possible treatments
- Popularity
- Connection
- The family sessions were incredibly informative, encouraging, and helpful.
- Unbelievable Support
- Great topics and speakers
- Sharing stories
- Learning daily
- Encouragement
- Fucose/ potential non diet treatment
- New Friendships
- G1D is a spectrum disorder.
- New and continued friendships
- Friendships
- Hope
- Hope💙
- Meeting other families
- Connecting with the other families!
- Supportive Community
- The people
- Community
- Hope for the future



Do you have a parting message for the community?

Open text poll  37 responses  34 participants

- Thankful for each of you! So grateful to share this journey!
- See everyone in gulf shores. Thank you
- Lots of hope gained
- The closeness of this group is wonderful!
- Thanks for all of the hard work you put into this!!
- Keep up the momentum and research
- This journey gets more manageable and less frightening with time - adult parent
- Can't wait to meet again in Gulf shores
- Keep ears open to studies.../ talked to the researchers who are there.//. Talked to others who are on
- We are a family and we're here for each other! Never stop advocating for your person
- Keep sharing your experience and GLUT1
- Thank you for everyone being a big family
- Don't stop
- Thank you and keep positive with hope
- You Rock Glenna
- You are not alone
- This is a marathon, not a sprint! Take one day at a time.
- Keep learning and ask questions
- Thank you for the great conference!
- Thank you!!!
- Keep on dojng
- GO GLENAAAA!!!!
- Thank you!! You are not alone! We're in this together!
- Continue to hope
- Stay connected- social media has been a game changer
- Keep advocating
- THANK YOU
- Keep the hope!
- Lean in and keep asking questions
- We are not alone!!
- Thank you!!
- Keep up the good work
- Reach out if you need help or support
- Keep talking
- Thank you!!!!!
- You got this!