At the 2019 KAND Family & Scientific Engagement Conference in New York City, we asked families affected by KIF1A Associated Neurological Disorder (KAND) to help people understand their challenges and what matters most to them. Here are their responses.

www.kif1a.org/2019conference/
The most challenging aspect of living with KAND is

- "progressive" idea & the related unknowns
- not seeing well
- living in an inaccessible world
- physical toll on family from lifting
- educating our doctors
- worried there won't be therapy or it's too late for my son
- uncertainty/unknown
- unknown future, no cure
- uncertainty
- not enough hours in day (4 kids, full-time job, special needs child). Never complete anything!
- not getting to see my child experience normal activities & milestones
- not knowing what the future holds for my son
- the unknown: what's my boy's life going to be? How long do we have?
- "Your child looks fine" from the outside
- people saying "they will grow out of it"
- not knowing the future
- how time consuming everything is, leaving little time with other family/kids/husband
- constant supervision of child, frustration with child
- unable to do things others can do & worry about keeping safe
- fear of the unknown
- seizures
- cleaning poop off carpet after our son self-removes nappy (diaper)
- battling with yourself to make the right choices for your child
- lack of community resources
- not being able to do everyday things as easily
The most challenging aspect of living with KAND is

- The future is unknown
- The time dedicated every day to make it normal
- Fear of the unknown
- All of the unknowns
- Knowing what is normal vs. is this a seizure? Is this KIF1A?
- Uncertainty
- Comparing your child to others
- Worrying about the future
- Uncertainty
- That our son is very aware & depressed, angry. It would be better if he didn't know.
- The unknowns
- Who's going to take care of him, when I won't be there anymore
- Seeing my girl suffer in respiratory distress
- Not knowing what's ahead
- Being scared of the future
- Sleep problems
- Numerous hospitalizations a year = life on standby
- Being isolated and scared of viruses all the time
- Having to take care of an eternal baby
- Involving the child with siblings & other children without KIF1A in everyday life
- The idea/scare of death
- Communication
- Degenerative disease; poor balance - falling;
- Communication & speech problems; vision problems
- The unknown
The most challenging aspect of living with KAND is ________________

- not knowing the future
- worrying about my child as she goes through life. How will she adjust?
- fear of what is to come
- the unknown about the future
- injuries
- the unknown
- keeping my daughter safe
- fear of the future
- the uncertainty of the future
- being independent
- seeing the kids and realizing that you may not be able to make a difference
- uncertainty
- it is a degenerative condition
- the fear
- can't cure it (YET!)
- not knowing what's gonna happen next
- uncertainty
- uncertainty
- uncertainty
- to be outside normal human families/society experience
- knowing his life is expected to be shortened
- the unknown
- the unknown future
- (un)consciousness for me as a mother
- never getting to see a first smile or hear a first laugh

(KIFIA KIFIA.ORG)
I want researchers & doctors to know

- what the future holds for my daughter
- my kid's name & family
- more therapeutic options & solutions
- we will not give up & my daughter is worth it
- this condition affects many more people than we know

- tell us what we can do, we will MOVE MOUNTAINS to make it happen. Seriously... ANYTHING.
- I am not an idiot. My child has a condition that causes...
- disabled people are worthy of time, attention and treatment
- my son is not just a number. He's a person.
- we are grateful

- our kids are worth it
- what has worked or not worked for other KIF1A kids
- ...about every aspect of my kid's condition, not just those relating to his/her specialty
- my child is a person too... She has feelings and can hear what you are saying
- I am not crazy... my child has real problems!

- his impairment may seem mild but it only affects them mildly, not him
- MORE
- they must be aggressive in order to win this race with KIF1A
- my child without having to explain his abilities every time

- I'm tired of the fact you have limited knowledge of KIF1A.
- I'm discouraged that you don't put as much into it as we do.
- I want them to know I'm capable
- a cure for KIF1A
- about the research into KIF1A and I want you to be involved

- STOP using a diagnosis like CP when you don't know what's wrong. Just say I don't know!
I want researchers & doctors to know

- the importance of continuity of care with all specialists
- will surgical intervention do more harm than good?
- how to slow the progressiveness of disease
- how to control seizures
- how to improve vision or at least halt deterioration
- it’s okay to say “I don’t know”
- prevent aspiration
- how to make progress matter
- he is blind not deaf (don’t scream at him)
- about KIF1A and rare diseases
- we know our kids & more than the doctors do about their condition at this stage
- what to do, what should be checked
- he is so sweet & not just a very sick person, he is a “normal” child
- we will do whatever we can to move the research/care/treatment process along
- that treatment is relatively soon!!
- how to cure my child
- I feel like nothing works
- so many therapies... Little progress
- I’m frustrated by their lack of knowledge & unwillingness to research the condition
- I want them to take it more seriously
- that we are scared & want to stop this disease from progressing
- everything that there is to know & to research it themselves. Don’t depend on us.
- I want them to do something
- more so they can diagnosis more kids and find a treatment
- we will do whatever we can to move the research/care/treatment process along
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If treatment can help anything, that would make a meaningful difference in our daily lives.

- my child tell us how he feels & what he wants
- my child’s happiness but being able to live as a full emotional being
- her friendships
- us to find a cure before it’s too late
- my son accomplish his life goals
- his quality of life
- a cure
- ensure things will be ok when I’m gone
- my child live on her own with adequate supports to live a rich life on her terms
- my daughter be happy & loved
- my child know she is loved & accepted as she is
- my daughter live a full & happy life
- my child be happy, safe & have a purpose to his life
- my child live safely but independently
- my daughter be happy & healthy
- my child be happy, able to learn & not in pain
- making EVERY moment count
- my son have a happy life
- my child to not be in pain
- my child to outlive me
- my child’s quality of life
- help him achieve everything he wants & is capable & interested in
- have a good relationship with his siblings
- my son live a normal life
If treatment can help ____________, that would make a meaningful difference in our daily lives.

- My child have a chance to live independently
- My child to enjoy his life
- My child be healthy & happy
- My child continue to improve & progress
- Him feel good about himself

- My child have a chance to live a fulfilled & happy life
- My child be safe & happy
- My child make a friend
- My son be able to look me in the eyes
- My child play with other kids

- Strengthen our daughter’s legs & increase her balance
- My daughter fall less & be able to keep up with her bro & sis
- My child tell me he’s hungry or if he’s unwell
- My child keep up with other children & stop falling
- The disease from progressing

- Cognitive impairment
- Her talking/communication
- My child tell me he’s hungry or if he’s unwell
- Maintaining mobility & improving memory function
- Her not get pneumonia every time she gets a cold

- My child walk & communicate better
- His vision
- My child communicate what hurts
- Control my child’s seizures
What matters most to me is

- Having my child walk independently & overcome cognitive delays
- My child having the coordination to do day-to-day tasks
- Having my child not get too tired to get into the tub (leg weakness)
- Stopping the progression
- Stopping things getting any worse

- My child being able to see better
- My child falling down less
- For my daughter to make faster progress
- My daughter following her interests & passions
- Having my son run without walking aides
- Educating others about KIF1A
- Stopping KIF1A progression
- Improving spatial awareness & balance/coordination
- Stopping the progression
- Decreasing seizures & repetitive behaviors; improving balance

- Preventing my child from falling
- Having my child communicate at all
- Stopping my child from having to worry about his safety
- My child’s ability to walk
- My child being able to walk
- Communication with my son
- My child having a future beyond KIF1A limits. My child has a full life.
- Knowing how will she be when I can’t help anymore
- Family
- My child not being in pain

My child has a full life. Knowing how will she be when I can’t help anymore
What matters most to me is

- my child being included in the community
- that he feels comfortable
- that he is safe
- that others see how amazing he is & not for his disability
- knowing that my kids will be cared for

- he is safe, comfortable, happy
- my child can somewhat grow up normal & happy and loving
- having a cure to stop the progression of the disease & a chance to heal
- my child's quality of life
- her happiness

- My child having a functional future & happiness
- my child's happiness
- my child is happy, smiling all the time
- my child is as happy & healthy as possible
- he's very loved & happy

- for my child to know he is loved!
- my child being independent
- my daughter's happiness
- daughter's ability to enjoy life
- her comfort; no suffering (no medical aggression)

- my child to live the best life she possibly can
- that he is happy, content & pain-free
- my child isn't suffering
- my child feels loved
- that her future is not run by KIF1A

- for him to be healthy & have a happy life
- that my child will be taken care of or can take care of herself if/when I can no longer do so
JOIN OUR MISSION TO CURE KAND AT KIF1A.ORG