




2019 KAND Conference Patient Perspectives Activity





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 KIFIA?

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 KIFIA 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

the uncertainty of the future

injuries

the unknown

keeping my daughter safe

fear of the future

the uncertainty of what tomorrow will look like

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

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

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 KIFIA 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 KIFIA

a cure for KIFIA

my child without
having to explain his
abilities every time

I'm tired of the
fact you have limited
knowledge of KIFIA.

I'm discouraged that
you don't put as much
into it as we do.

I want them to know
I'm capable

STOP using a
diagnosis like CP when you
don't know what's wrong.
Just say I don't know!

about the research
into KIFIA and I want
you to be involved

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 KIFIA 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

If treatment can help _____, that would make a meaningful difference in our daily lives.

anything

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 child 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

him to tell us if he is in pain

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 KIFIA

stopping KIFIA 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 KIFIA 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

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

to always have good people around & live a normal/regular life similar to his peers

my child is as happy & healthy as possible

for my child to know he is loved!

my child being independent

my daughter's happiness

daughter's ability to enjoy life

he's very loved & happy

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

her comfort; no suffering (no medical aggression)

that her future is not run by KIFIA

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



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CURE KAND AT
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