Our Contact Information

that are being developed now will work. But we do know that we are

yourself. Fight for your family

are doing, I welcome them and simply ask that you frame them constructively. And please

parent meetings and

families impacted by KCNT1.

WE ARE HARD AT WORK AND MAKING PROGRESS.

their pipeline of drug development. We also had the chance to tour the lab at Vanderbilt

American Epilepsy Society

some key events and now our Foundation is well recognized by industry leaders,

helping us complete some important tasks. We are speaking with other universities as

genetics program and the pre-med undergraduate program at Vanderbilt to get students

right code, your insurance company will generally cover the cost of the treatment for a

personally feel might work best. Our goal is to gather hard data and have our clinicians

cerebrospinal fluid circulates between the brain and spinal cord). For small molecules,

your EEGs in EDF format.

the US to look for specific signals in the EEGs of children with KCNT1 that could be used

and a pharma team working on a novel approach to treat KCNT1.

drugs can be designed to only treat compromised areas of the brain. By avoiding the

that the first question most pharma teams ask is

children respond better to a drug than others, a diverse asset library will allow pharma to

what institution to intuition transfer agreements do in 4-6 months. This means less time

My son, Andrew, was the first to have a blood sample sent. We are inviting any interested

these assets. But it takes time, typically several months, for these groups to negotiate

They can develop their own cell lines which takes 3-6 months, (Pharma cannot contact

Why create a biobank if researchers already have cell lines? When we send samples from

US.

Biobank

Foundation to make sure we were one of the first diseases included in the program, and

significantly reduces the time we wait for future trials. It also ensures interest from a wider

This means that when the second, third, and fourth drug companies go to the FDA to

NHS. But there is a key difference: the data that you provide when you sign up (takes 15

home natural history study (NHS) program to make it significantly easier for parents to

Patient

The Patient

Foundation ultimately helped bring in a major funding partner to this program.

molecule program for KCNT1. The timeframe for a program like this is 7-10 years to bring

potential, but there is considerable work yet to be done to develop a drug that could enter

not communicate regularly with this team, but from what we are told there is at least one

participate in next year.

identified and validated in KCNT1 models. We are currently working with teams in three

Program 6

UCB brings substantial funding

database, participating in the Patient Registry, and signing up for a Citizen account. The

work on at the KCNT1 Epilepsy Foundation. I am proud so share that we have made

this and so much more we are grateful going into 2023.

To fellow KCNT1 Epilepsy family members;