

## **A GIFT OF: LIFE, LOVE, COMFORT, BLESSINGS, HELPING, and HOPE!**

How to pass on a Gift that will continue to Bless our Glut1 Families. A gift will Pay Life Forward by donating your Glut1 family member's tissue to our researchers.

Tissue donation is different than Organ donation. Organ donations and transplant needs to be done within hours. Tissue donations can be collected up to 24 - 48 hours after death. With tissue donations any incisions made can be closed if an open casket for the funeral is wanted.

1. Please discuss whether or not you would want to donate to the tissue repositories. It may be something you hadn't thought about so if you should ever have to make this type of decision you will all be in agreement. Our son would be so Proud of us for donating his tissues. We have God's PEACE in our heart and our Faith has shown us God's Plan for Drew.

### 2. Action Plan

Put the contact information for the tissue repositories in your cell phones.

Suggestion:

- a. First name line: Put the full name of the person in charge all on first name line.
- b. Last name line : Put - GLUT1 Tissues.
- c. Company line: Put the biopository name.
- d. Office Phone number in the add phone line.
- e. Additional phone number add cell phone
- f. Email address in the add email line.
- g. Notes: Add information...did you preregister? Passwords.

Having the information stored on your phone in this way you could search Glut1 and both repositories would come up and you can send an email or text right from your phone.

### 3. Update information as needed.

Personal may change so you would need to change their name which may need to change phone numbers and emails. The Glut1 Deficiency Foundation will also keep everyone informed.

4. There is a way to pre-register with both biorepositories. I would have you email each of them and set this up. Not only would it save time but then you do not have to do it in your distressed state.

This is the information I have today for the biorepositories.

**Dr. Pascual:**

**A BRAIN BANK FOR RARE AND UNDIAGNOSED DISORDERS**

Contact person : Sharon Primeaux

Office phone: 214-648-2645

Cell phone: 512-563-4575

Email: [Sharon.pimeaux@utsouthwestern.edu](mailto:Sharon.pimeaux@utsouthwestern.edu)

**COMBINEDBrain.org for other researchers studying Glut1**

COMBINEDBrain Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders

Contact Person : Taylor Morris

Office Line: 615-2898216

Direct line: 210-478-6119

Email: [taylormorris@combinedbrain.org](mailto:taylormorris@combinedbrain.org)

5. When faced with a Loved ones' passing
  - a. If in a hospital / emergency room setting let the physicians know immediately that you will be donating to the above listed repositories. Contact the repositories right from your phone if you have already entered the information. If not search the Glut1 web site (under research tools) for the information or if you wrote it out and kept in your file system ask someone to retrieve it.
  - b. If at home let the ambulance personnel know and contact the repositories (not sure but the person will be taken to the morgue where if you are not having an autopsy you will need to tell them you will be collecting tissues for Glut 1 repositories).
  - c. If having an autopsy done let the medical examiners know your wishes and contact the repositories.

We looked at all your beautiful faces at the conference and those of you who will be reading this and know we have given ALL of you the Gift of HOPE and that HOPE will continue to Bless us and our Glut1 families for generations.

OUR LOVE to each and everyone of you!

Jim and Pat Hemlock