Genetic/Metabolic Health Care Delivery During and After Hurricanes Katrina and Rita

Jess Thoene*, MD, Hans C. Andersson*, MD, TC Narumanchi, MD*, Amy Cunningham*, Bruce Bowdish#, PhD,

Aftermath of Katrina:

- In Louisiana alone,
- >1000 dead
- >100,000 homes lost due to flooding
- Fewer than 70,000 residents now live in New Orleans(prior to the storm, >500,000)
- No public schools open
- 4 private schools open
- 40% of city lacks power, water, gas
- Cell phones, land lines and computers down

For Metabolic/genetic Patients

- How do Drs find each other?
- How do our patients find us?
- How do we obtain lab testing?
- How do we supply formula and Orphan meds?

Immediate solutions:

- Text messaging works when cell phones don't
- Phones in other area codes can call in when 504 is down
- Many offers of lab help received: Kehler, Blitzer, Tuchman, Elsas
- Parents willingly shared scarce meds with strangers with same Dx as their child
- FEMA granted emergency approval to pay for meds

Long term proposals

- Communications: 1-800-911-GENE
- Orphan Products: Stockpile critical meds for distribution within the disaster area: Urea cycle meds, carnitine, Cystagon, B12, tetrahydrobiopterin
- Guaranteed courier service- use Federal or National Guard troops initially

Long term solutions (Cont'd)

- Emergency patient instructions- distribute via 1-800-911-GENE
- Create a hierarchy of labs and clinicians in all regions willing and trained to respond to such events