

Carnitine Transporter Deficiency (Carnitine Uptake Deficiency) Ages 18+ years

Clinic Visits:

- Every 3 years

Laboratory studies:

- At clinic visits:
 - Carnitine levels

During illness:

- Call the Metabolic Clinic to alert them immediately if you are sick
 - Poor feeding, vomiting, and/or lethargy
- Take glucose gel or polymer solution if needed (or instructed to do so)
- If you are not able to keep down glucose containing fluids, you will need to go to the emergency room for IV 10% dextrose (glucose)
- Be sure to bring Emergency Room letter with you to the hospital
- Labs during illness include: comprehensive metabolic panel, ammonia, serum CK (muscle health) and B-type Natriuretic Peptide (heart health)
- Please alert the Metabolic Clinic if you need surgery
- Consider Medic Alert Bracelet**

Evaluations:

- Cardiology evaluation every 2 years (with possible halter monitor)

Topics:

- Biochemistry and genetics of Carnitine Transporter Deficiency
- Diet/management
 - Avoid fasting
 - Carnitine supplementation
 - Management during illness

Please make sure your clinic visits and laboratory studies are done on time. Call the Metabolic clinic at _____ to make an appointment, schedule a blood draw, or with any other questions. If you urgently need to reach a Metabolic physician, call _____ and ask to page the Metabolic physician on call.

Thank You,

Your Metabolic Team