Introduction
The Mitochondrial Functional Disorders Program serves to provide a comprehensive outpatient evaluation of children through young adults (birth to age 21) who suffer from a variety of functional disorders that often have low cellular energy (mitochondrial dysfunction) as one cause. Many times, but not always, the mother and other maternal relatives also suffer from various types of functional symptoms as well.

What Are Functional Disorders?
We use this term to refer to the large and related group of conditions for which consistent “structural” anomalies are not found, and in which disease is believed to be caused by abnormal cellular function. This does NOT make the condition any less real, or mean that the patient suffers any less. Some of these conditions are traditionally considered to be related to “medical” or “physical” health and others to “mental” or “psychological” health. Our philosophy is that all of these conditions are likely related to each other and have a physical cause.

What Functional Disorders Does the Program Evaluate?
• Cyclic vomiting syndrome, abdominal migraine
• Migraine headache, reflex sympathetic dystrophy and other chronic pain disorders
• Severe gastrointestinal dysmotility, chronic functional abdominal pain
• Chronic fatigue syndrome
• Ketotic hypoglycemia, fasting intolerance, episodic metabolic acidosis
• Many others

What Is the Purpose of the Program?
• To provide a comprehensive evaluation of the patient in order to make recommendations for the local care team to enable them to better care for the patient.

What Does This Comprehensive Evaluation Comprise?
1. A pre-visit evaluation of the medical records, followed by a written report regarding our initial recommendations. This allows us to:

• Request additional existing records for the team visit so that your visit will be more informative and helpful.
• Request your care providers order additional testing prior to the visit.
• May suggest one or more treatment options while you are awaiting the visit.
2. A half-day to all-day comprehensive in-person evaluation at Childrens Hospital Los Angeles, which is ranked as the #1 children's hospital on the west coast. This evaluation will be conducted by our team, whose members are all highly trained in the evaluation and care of individuals with functional disease and with mitochondrial/metabolic disorders. This team consists of:

**Physician - Richard G. Boles, M.D.**
Dr. Boles is a physician who is board certified in Clinical Genetics, Clinical Biochemical Genetics (metabolic disorders) and Pediatrics. Dr. Boles is a faculty member at the USC Keck School of Medicine with over 20 years of experience in the evaluation and treatment of patients with metabolic/mitochondrial disorders, and for the last decade has concentrated his efforts predominantly on functional disorders. Dr. Boles has been funded by the National Institute of Health, the United Mitochondrial Disease Foundation, and private foundations. Dr. Boles has published over 50 peer-reviewed medical/scientific articles, primarily in his areas of focus on mitochondria and/or functional disease. Dr. Boles will construct an overall care plan with the input of other team members and the family.

**Genetic Counselor**
One of the program's genetic counselors will be assigned to your family. The genetic counselor is your direct and personal link with our team. Most questions that are not of a logistical nature (appointments, insurance, etc.) are first directed to the genetic counselor. In addition, the genetic counselor will act as a liaison between our program and your other care providers. The genetic counselor will also assist your family in terms of understanding the risks to current family members, including any family planning issues that you might have.

**Metabolic Dietician**
One of the program's metabolic dieticians will be assigned to your family. Much of the treatment for these conditions is dietary, and the metabolic dietician will assist you and your family regarding the goals of dietary therapy and how to achieve those goals in practical terms. The metabolic dietician will also help with issues related to any vitamin or cofactor therapy.

**Social Worker**
One of the program's social workers may be assigned to your family. The social worker's main function in our program is to assist families with issues regarding educational testing, treatment programs, and accessing other public and private resources that might benefit the patient. The social worker can also assist you in terms of any financial or legal issues that your family may have related to the illness.

3. A post-visit evaluation of treatment responses and/or test results. Our recommendations given during the above visit are likely to include various treatments and additional testing. Our team will meet a few months after the visit to review the results of any treatments and testing. You will receive another written report regarding these results, and if and how they have altered our previous recommendations. The timing of this review will vary depending on the circumstances.

**How Much Will This Cost Me? (Financial Arrangements)**
We estimate that, if we add together all the individual fees for services delivered to the average patient, the total charges for the services rendered by both the Childrens Hospital Los Angeles Medical Group (physician) and Childrens Hospital Los Angeles (other team providers) will be approximately $3,500.
However, the amount your family will need to pay out of pocket will be determined by the actual services your child requires and the amount your health insurance plan will cover.

Health insurance coverage is complicated and coverage varies by insurance plan. We expect that your insurance company may agree to pay for some services and not others. The following is an overview of what many insurance plans may or may not cover:

**Covered Services:** For those services your insurance company agrees to cover, they likely will still not pay the entire amount. Under the terms of your insurance coverage, you may have a deductible, copay, or coinsurance amount that is your personal financial obligation. When you make an appointment, we will verify your insurance coverage and Childrens Hospital Los Angeles Medical Group and Childrens Hospital Los Angeles will bill your insurance carrier for covered services. Your insurance company, however, will make the final and official coverage decision once the insurance claim has been submitted and you will be fully and personally responsible for the amounts your insurance company does not pay.

**Services Not Covered:** The services that are not generally covered by insurance include an extensive pre-visit work-up and evaluation, the Qualitative Pedigree Analysis™, and special reports for the coordination of care amongst your child’s various local providers. The charges for these pre-visit services are $1,200, due in advance of your child’s visit, and are considered a nonrefundable deposit prior to the medical record review. In addition, if your insurance company informs us at the time your insurance is verified that they will not cover certain services provided during the visit, the charge for these services will be due at the time of the initial visit.

We estimate that the average family will have an out-of-pocket expense of approximately $2,000 for the above-listed services. Any subsequent clinic visits are not covered. Of course, if your insurance company covers more or less than the average amount, the amount that you will be personally responsible for will be lower or higher, accordingly.

We hope this information is helpful as you make your decision to schedule an appointment. Please feel free to call us at (323) 361-8600 or e-mail at maperez@chla.usc.edu with any questions.
Signature

I have read this description of the Mitochondrial Functional Disorders Program, including the Financial Arrangements, and have been given the opportunity to ask questions about what to expect from this program and acknowledge my personal responsibility to pay for the services to be rendered by both the Childrens Hospital Los Angeles Medical Group and Childrens Hospital Los Angeles not covered by my insurance plan. I am requesting that I/my child be evaluated as a patient in the Program. I agree to the terms of this Program, including my responsibility to pay for any services not covered and paid for by insurance.

______________________________  ____________________________________
Parent's Name     Patient's Name

_______________________________  ____________________________________
Parent's Signature    Patient's Signature (if 18 years or older)

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Date