



# Mitochondrial and Molecular Medicine

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Medical Genetics

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## New Family Patient and Clinician Expectations and Consent Form

**Purpose:** In the context of a private practice in Medical Genetics, this practice seeks to apply the power of advances in medicine, particularly in DNA sequencing, to provide the best possible medical care to you/your child.

**Personal statement:** My career and passion for the last 20 years has been to bring the functional and autistic disorders into the medical mainstream. I do not believe that people who suffer from chronic and severe pain, nausea, or fatigue should be told that there is nothing “real” going on, nothing that can be tested for, and nothing that can be treated. I do not believe that parents of a child with autism should be told that further diagnosis and treatment are unavailable or inappropriate. Recent advances in genetics have exploded in the last several years regarding the genetic and environmental factors that can contribute towards all of these conditions and more. Unfortunately, very few physicians use this advancing knowledge, even at the major medical and academic centers. In my experience, most patients with these conditions improve with a genomic (DNA sequence)-based approach, many dramatically so, although not all do. If you or your child becomes my patient, I cannot promise you that we will find underlying causes or factors for your/your child’s disease. I also cannot promise you that any causes or factors that are found will be treatable, or that the treatment will work. What I am promising you is that I will *really* listen to you, that I will suggest any testing, DNA sequencing or otherwise, that might help understand the disease better, and that I will discuss with you any appropriate treatment options.

Additional information regarding Dr. Boles is present on page 5-6.

**Practice Requirements:** patients must meet all of the following to get an appointment for an evaluation:

- Disease: One or more of the following:
  - a. *Mitochondrial disease or dysfunction*, including suspected cases.
  - b. *Any autistic spectrum disorder* including autism, Asperger, or pervasive developmental disorder.

- c. *A complicated migraine-like illness* such as *cyclic vomiting*, hemiplegic migraine, episodic ataxia (balance loss), etc.
  - d. *“Functional disease”* as defined by at least 3 of the following: autism, ADHD, chronic fatigue, migraine (including the common varieties), muscle pain or other chronic pain (including CRPS/RSD), GI dysmotility (including IBS), dysautonomia/POTS, or mood disorder (anxiety, depression, bipolar, panic attacks). Similar functional/dysautonomic findings might also apply.
- Age: Under 25 years (sorry, being a pediatrician, this is an insurance issue; the age limit may increase later). I can see a limited number of patients up to age 29 years.
  - Agreement: Acceptance of all of the conditions of this practice, as per this letter, including the financial terms.

Email me if you are not sure if you/your child meets these criteria. Also, I do make an occasional exception.

**Novelty:** Recent advances in DNA sequencing technologies have opened the door to vast knowledge that was not previously available. In particular, this practice seeks to utilize massive DNA sequence information in medical practice. This is NOT research, in that the overriding purpose of the practice is to provide you/your child with medical care. **However, the care provided often is personalized and/or innovative, in that it is targeted to the unique aspects of the patient and family, including DNA sequence data.**

**Scope:** Patients seen by Dr. Boles are expected to have a primary care physician, and in most cases additional specialists, to follow the patient throughout the year. **Dr. Boles’ practice is predominately quaternary care, meaning that the intent is to advise the various specialists, as well as the primary care physician, caring for you/your child.** Follow-up visits generally are scheduled semi-annually or annually (often dependent on how far away you live and your ability to travel), but in some cases other schedules are appropriate. You also may chose to have an initial evaluation with Dr. Boles but to seek follow-up elsewhere.

**Communications:** Patients in this practice are generally complicated and issues may develop in between office visits. **Email is the primary form of communication**, both with the family and with other providers as needed. On occasion, other forms of communication may be appropriate. The office consultation note will be delivered by email to the patient/family, and any other providers as desired by the family, generally on the same day as the office visit. **By joining and continuing to be followed in this practice, you are consenting to email communications.** Email is not checked 24/7/365, so **urgent and emergent requests should not be handed by email.**

**Emergencies:** Dr. Boles tries to be available to his patients, but provides no urgent care or emergency services. For true emergencies, call 911. Urgent/emergent services are to be handled through the primary care and/or specialists following the patient, and/or the emergency room. In particular, Dr. Boles travels frequently to deliver lectures, and is not always available.

**DNA Sequencing and Potential Conflicts of Interest:** DNA sequencing is an integral aspect of the medical care model utilized in this practice. Dr. Boles was a full-time consultant to Courtagen Life Sciences Inc. until the company went out of business in June 2017. In the future, Dr. Boles may serve as a consultant to other laboratories, and thus may benefit financially upon the success of that company. However, [Dr. Boles will always provide you with the best options for you/your child to suit your/your child's individual needs. This is the case whether Dr. Boles has a financial interest in the company providing the test, the test is offered by a competitor, or neither of the above.](#) Dr. Boles will tell you if he has a financial interest in any laboratory or product that he recommends. You are under no obligation to choose any testing or products recommended by Dr. Boles whether or not he has a financial interest in it.

**Appointments:** Please email Dr. Boles regarding requests for appointments at [drboles@molecularmitocom](mailto:drboles@molecularmitocom).

**Medical Records for Dr. Boles to Review:** Please send pertinent medical records to Dr. Boles, preferably by email and at least a week ahead of the visit. Mailing a DVD is also a good option. Paper records can be reviewed at the visit, but will take time away from the visit. The medical records that are most helpful are:

1. Sub-specialist evaluations (e.g. neurologist, gastroenterologist, geneticist)
2. Certain hospital records (e.g. admission, discharge, operative, sub-specialist consultation)
3. Specific testing (e.g. DNA/genetic, biochemical/metabolic, biopsy, MRI, endoscopy)
4. Most-recent laboratory results (e.g. CBC, chemistry panel, coenzyme Q10, carnitine and/or amitriptyline blood levels)
5. Growth chart for height and weight

Please do not send the actual films, for example from an MRI, but instead sent the written interpretation.

**Payment for Dr. Boles' Services:** [The charge for new appointments is \\$1,200 for about a 2 to 3-hour visit.](#) If there is more than one person being seen as a new patient, such as a sibling, there is an \$800 charge per additional patient. The first-half of the initial office visit (\$600 if one patient is seen) is due within 30 days of scheduling the appointment. Payment for the second half of the initial visit is due at the time of the visit.

Follow-up visits are generally scheduled for one hour, given the complexity of the patients seen. The charge is \$500 and is due at the time that services are provided.

Payment options:

- Credit card
- PayPal

For the initial payment, to send money safely and easily by PayPal, email the following to Dr. Boles: credit card number, expiration date, the ZIP code for the billing of your credit card, and your cell phone number, but do NOT put the 3-4 digit (CSC) number in that email. Send the CSC number to me at [richard.boles@neuroneeds.com](mailto:richard.boles@neuroneeds.com), and make sure to include the patient's name on that email. This way, no one can use this information to "hack" into your account, and you don't need to know how to use PayPal and do not need that app.

Initial and follow-up visit fees include a reasonable amount of email communications through the year to the family, and to other care providers, as appropriate. Services beyond this will incur separate charges, for which you will be made aware of before the services are provided. There are no hidden or unexpected charges.

**Insurance:** Dr. Boles is not a member of any third-part contracts, meaning that he is "out-of-network" for all payers. This is a "cash practice". It is anticipated that most PPO patients will be reimbursed a proportion of their payment, dependent on your insurance plan, deductible, and other factors. Upon request, Dr. Boles will provide you with the documents needed for you to apply for partial reimbursement from your insurance company. Additionally, Dr. Boles does not accept government plans such as MediCal/Medicaid, Medicare, and California Children's Services (CCS).

**In-Patient:** Dr. Boles does not have admitting privileges to any hospital. You may contact Dr. Boles if you/your child is going to be admitted to a hospital. Oftentimes, an email or telephone communication between Dr. Boles and the in-patient physician is indicated to help ensure that you/your child receives the appropriate care. However, because of laws and protocols, the physician must contact Dr. Boles requesting advice. These communications are, within reason, included in the office visit fee.

**Payment for Laboratory Testing and Other Services:** Whether ordered or suggested by Dr. Boles, payment for all testing and other services are to be arranged and paid for by the patient, family, and/or insurance company.

**Telemedicine:** Since the start of the Covid-19 pandemic, Dr. Boles has been exclusively evaluating patients via telemedicine. He believes that this is very close to being physically in his office, except without the travel. Families have almost universally preferred this. Telemedicine has been working so well that there are no current plans to return to in-person evaluations. Telemedicine appointments are performed by Zoom, and you will receive an email invitation, usually the previous day or on the day of the scheduled appointment. A laptop or desktop computer work better, but a tablet or phone can be used. Have adequate light in front of you, and not behind you.

**State licensure:** Telemedicine legally occurs in the state where the patient is located at the time. Due to the Covid-19 pandemic, the federal Department of Health and Human Services in December 2020 overruled state licensing laws and allowed telemedicine for a licensed physician in all 50 states. Thus, at the time of this writing, Dr. Boles can evaluate you/your child anywhere in the United States. However, it is unclear how long this situation will last. Dr. Boles has a medical license in 5 states (AZ, CA, FL, NJ, PA), and following the pandemic-

related emergency it may be necessary for the patient to physically travel to one of these states for a telemedicine evaluation to be legal. This should not affect the ability of Dr. Boles to explain to you the result of laboratory tests that were legally ordered previously.

**Separate Practices:** This is a solo private practice that is completely independent from any other entities.

**Research:** In addition to providing patient care, Dr. Boles is collecting data in order to improve, care, educate other physicians/providers, and learn more about these conditions. The ultimate goal of this data collection is to improve medical care. Your/your child's medical information will be used in this data analysis by Dr. Boles and any investigators under his supervision in accordance with applicable law. No personal identifying information will be published or presented to others without your specific permission. Examples of information NOT released without your approval includes names, photos, and enough detail so that the family/patient could be identified (example: a detailed pedigree). [By joining and continuing to be followed in this practice, you are consenting to the use, publication \(both print and electronic\) and presentation of non-identifying information, in a manner similar to that of academic medical institutions, as permitted by law.](#)

**Obligation and Options:** You are under no obligation to join and/or continue to be followed in this practice.

**Change in Terms:** Changes will likely be necessary for ideal functioning. You will be informed of changes that affect you/your child, and you always have the opportunity to seek care elsewhere.

**Summary:** This document is a summary of the practice opportunity and cannot possibly cover every issue. Please ask Dr. Boles for any specific questions or clarifications.

I am the patient, parent, or legal guardian, and I request that I/my child join this practice. I have read the above, had the opportunity to have any questions answered to my satisfaction, and I agree to the above terms:

Your Name: \_\_\_\_\_

Name of Patient (if different): \_\_\_\_\_

Relationship (circle): Patient Parent Other (please specify) \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Sincerely,



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