

NEW PATIENT LETTER

Dear future patients and families,

Thank you for your interest in coming to the Genetics Clinic. Please complete this questionnaire to the best of your ability and mail or fax it to our office at: Phoenix Children's' Hospital, Division of Genetics and Metabolism, 1920 E. Cambridge, Phoenix, Arizona 85006. Our fax number is (602) 933-2415. **Please return it prior to your appointment.** If you are not able to do so, please arrive 30 minutes early in order to fill it out when you arrive as it will need to be completed prior to being seen.

What is clinical genetics?

Genetics refers to the basic units of inheritance (genes) that determine growth, function and development of all living organisms. Clinical genetics is a medical subspecialty that provides evaluation, diagnosis, counseling and care to families and individuals affected by or at risk for birth defects and/or genetic conditions.

Who benefits from a genetic evaluation/counseling appointment?

Individuals who may benefit include those with birth defects, chromosome differences, suspected or known genetic conditions, intellectual disability, developmental delay or regression, suspected metabolic disorders and individuals with a family history of the above.

What will happen during the appointment?

A typical genetics evaluation begins with an information gathering session with the genetic counselor in which you will talk about your concerns for the visit and the patient's medical, developmental and family history. A physical examination is performed by one of our MD geneticists and is followed by a discussion of the findings and their recommendations. You will be able to ask questions and voice concerns at any time during the evaluation. If a diagnosis is made, we will provide you with comprehensive information including the nature of the condition, prognosis, recurrence risk, available resources/options and recommendations for medical management. If testing is ordered, a follow up appointment must be made to go over the results with the physician. Please plan to spend 2 hours at our office (including time for registration/check-in, meeting with a genetic counselor and the evaluation by the MD geneticist.)

Will genetic testing be done during the appointment?

The geneticist may recommend DNA and/or chromosome testing after the evaluation. Some genetic tests can be done using a blood specimen and others may be done using a cheek swab or saliva sample. Some genetic tests can be done at the time of the appointment. However, many genetic tests cannot be done the same day as the appointment because they may require a prior authorization or predetermination of insurance coverage. It may take several weeks for this prior authorization process to be completed.

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What do I need to do to prepare for this appointment?

1. **Medical Records** –In order to make your evaluation as complete and helpful to you as possible it is essential that we have your/your child's medical records to review BEFORE your visit. Note that it may take several **weeks** to receive these records.

Please request your/your child's medical records to be sent to our office.

- Fill out the enclosed records release form with your child's information and sign/date at the bottom.
- Check the boxes pertinent medical records, consultations, lab & x-ray reports
- Makes as many copies as necessary for all of your/your child's specialists and send to THEIR offices requesting they send us your child's reports.
- We would like records from any specialists' evaluations including cardiology, endocrinology, neurology, ophthalmology, & all relevant test/imaging results.
- Please DO NOT send this form back to us, but to the other doctors.
- 2. **Family photographs** Please bring photos of the patient's close family members and of family members who have had similar symptoms or concerns as the patient. Looking at photographs of family members often provides helpful clues in a genetics evaluation.

How do we pay for the appointment?

Most insurance companies cover the cost of a genetic evaluation (similar to any other specialist visit). Make sure to bring the patient's insurance card(s) to your appointment.

We hope that this information is helpful to you. Please call our office if you have additional questions. Thank you for taking the time to complete this questionnaire. We look forward to meeting you soon.

Sincerely,

Division of Genetics and Metabolism Phoenix Children's Hospital 1920 E. Cambridge, Suite 304 Phoenix, AZ 85006

Phone: (602) 933-4363 Fax: (602) 933-2415

PCH10690 (Rev. 6 (12-2016) Page 2 of 2