

Checklist for Parents

Birth to 1 month: Newborns

At the Pediatrician's Office

- Ask the doctor to discuss the diagnosis of WAGR syndrome with you, and to explain the results of the genetic testing. Try to have someone with you at this visit, such as your spouse or a trusted friend or family member.
- Ask the doctor to review your child's physical examination with you, and if possible, your spouse or other close family member as well.
- Ask the doctor for copies of all lab test results and reports from specialists. Keep these copies in a medical file at home. In time you will find this file to be very helpful.
- Ask lots of questions. You may want to write your questions down before the visit, take them with you, and record your answers.

Ask the Doctor About

- Will your pediatrician help you to manage and coordinate the various medical specialists?
- Wilms tumor
 - When will the first ultrasound be done?
 - When and where will ultrasounds be done every three months?
 - Who will call with the results and when?
- Teach you to check your child's abdomen in-between ultrasound exams (if you are comfortable doing this)

Referrals You May Be Given

- Genetics** It's important for a geneticist to confirm the diagnosis, to order further testing if necessary, and to follow your child's progress as he grows
- Pediatric Ophthalmology** Children with Aniridia should be seen by an eye doctor who specializes in children, if possible
- Urology** If your child has external genital abnormalities, like hypospadias or undescended testicles

Checklist for Parents

1 Month to 1 Year: Infants

At the Pediatrician's Office

- A physical examination, including a thorough abdomen check, will be done at each office visit
- Laboratory tests, including complete blood count, if necessary, and urine test to check for blood in the urine
- Ask lots of questions

Referrals You May Be Given

- Genetics** to confirm the diagnosis, and to order additional tests, if needed
- Urology** a specialist in genital and/or problems with urinary tract
- Hematology/Oncology** cancer specialists for Wilms tumor treatment tumor, if necessary
- Early Intervention Services** services and therapies to maximize mental and physical development
- Pediatric Ophthalmology** eye doctor for children

Ask the Doctor About

- results of
 - genetic tests done since the last visit
 - consultations with specialists
- copies of
 - reports from other medical specialists
 - laboratory test results
 - keep these in your child's Medical File at home
- your child's history of ear infections or other illnesses like pneumonia. If there have been many of these, should there be any changes in the treatment plan?
- monitoring for Wilms tumor
 - ultrasounds scheduled every 3 months
 - checking for lumps in your child's abdomen at home in-between ultrasounds
- your child's growth and development
 - referral to Early Intervention Services

Checklist for Parents

1 to 5 Years: Early Childhood

At the Pediatrician's Office

- Physical examination, including a thorough abdomen check, will be done at each office visit
- Laboratory tests, including:
 - complete blood count
 - "lipid profile" (complete test for cholesterol)
 - urine test to check for blood and/or protein in the urine

Referrals You May Be Given

- Hematology/Oncology** cancer specialists for treatment of Wilms tumor if needed
- Pediatric Neuropsychiatry** specialist in diagnosis and management of behavior disorders
- Pediatric Ophthalmology** eye doctor for children
- Nephrology** kidney specialist
- Otolaryngology** ear, nose and throat specialist
- Orthopedics** muscle and bone specialist
- Dietician** to help with diet, nutrition, and weight management
- Pediatric Dentistry**
- Pediatric Gastroenterology** specialist in digestive problems

Ask the Doctor About

- helping you to coordinate and manage the medical specialists
- copies of
 - reports from other medical specialists
 - laboratory test results
 - keep these for your child's Medical File at home
- your child's behavior
 - discuss symptoms of behavior disorders
 - request a referral if necessary
- your child's activity level and sleep patterns
- ear, nose, throat and respiratory infections
 - does your child have more of these than a typical child?
 - should the treatment plan be adjusted to allow for prompt diagnosis and treatment?
- Wilms tumor
 - peak occurrence is between ages 1 and 3 years
 - Are ultrasounds scheduled every 3 months?
- your child's motor development
- your child's weight and growth
- your child's social skills and intellectual function
- are additional services or referrals needed?

Checklist for Parents

5 TO 13 YEARS: LATE CHILDHOOD

At the Pediatrician's Office

- A physical examination, including a thorough abdomen check, will be done at each office visit
- Laboratory tests, including
 - A complete blood count
 - A "lipid profile" (complete test for cholesterol)
 - A urine test to check for blood and/or protein in the urine
- Blood pressure check

Referrals You May Be Given

- Hematology/Oncology** cancer specialist for treatment of Wilms tumor if needed
- Pediatric Neuropsychiatry** for diagnosis and management of behavior disorders
- Pediatric Ophthalmology** children's eye doctor
- Nephrology** kidney specialist
- Orthopedics** muscle, bone, movement disorders
- Gynecology** specialist care for females
- Dietician** for nutrition and weight management
- Pediatric Dentistry**
- Pediatric**
- Gastroenterology** specialist in digestive problems

Ask the Doctor About

- helping you to coordinate and manage all the medical specialists
- copies of
 - reports from other medical specialists
 - laboratory test results
 - keep these in your child's medical file at home
- tests for females with WAGR syndrome
 - girls with streak ovaries may be monitored at with either pelvic ultrasound or MRI
- chronic kidney disease
- your child's behavior
- your child's activity level and sleep patterns
- Wilms tumor
 - Wilms tumor has been diagnosed in people with WAGR syndrome as late as age 19
 - some surveillance should continue throughout life
- your child's weight
- school and classroom placement
- are any additional services or referrals needed?

Checklist for Parents

13 TO 21 YEARS OR OLDER: ADOLESCENCE TO ADULTHOOD

At the Pediatrician's Office

- A physical examination, including a thorough check of the abdomen, will be done at each office visit
- Laboratory tests, including
 - complete blood count
 - "lipid profile" (complete test for cholesterol)
 - urine test to check for blood and/or protein in the urine
- Blood pressure check

Referrals You May Be Given

- Hematology/Oncology** cancer specialists for followup after Wilms tumor treatment
- Neuropsychiatry** for diagnosis and management of behavior disorders
- Ophthalmology** eye doctor
- Nephrology** kidney specialist
- Orthopedics** muscle, bone, movement disorders
- Gynecology** specialist care for females
- Dietician** nutrition and weight management
- Dentistry**
- Gastroenterology** specialist in digestive problems

Ask the Doctor About

- helping you to coordinate and manage medical specialists
- copies of
 - reports from medical specialists
 - laboratory test results
 - keep these in your child's medical file at home
- tests for females with WAGR syndrome
 - girls with streak ovaries may be monitored with either pelvic ultrasound or MRI
- chronic kidney disease
- your child's behavior
- your child's activity level and sleep patterns
- Wilms tumor
 - Wilms tumor has been diagnosed in people with WAGR syndrome as late as age 19
 - surveillance should continue throughout life
- your child's weight
- school and classroom placement
- transitioning to adulthood
 - vocational training, sexuality, guardianship, independent/semi-independent living options, transferring to adult medical care
- are additional services or referrals needed?