

# ADULT CONGENITAL HEART DISEASE CLINIC

## *Information for Patients and Families*



### ***What is the Adult Congenital Heart Disease (ACHD) Clinic?***

Congenital heart disease is heart disease present since birth. At the UW Medicine Adult Congenital Heart Disease (ACHD) Clinic we evaluate and care for patients born with heart disease. Your care team will include:

**Attending Doctor:** Your attending doctor is a board-certified cardiologist who works with you and the consulting specialists to determine your care plan. The attending doctor has completed all training to be a cardiologist and supervises all doctors in training and other staff who might participate in your care. This doctor also approves all decisions about your care plan.

**Advanced Registered Nurse Practitioner (ARNP):** An ARNP has a Master's of Science in Nursing and advanced medical training in the assessment, diagnosis and treatment of patients. Your ARNP is licensed to diagnose and prescribe medicines and works with your attending doctor in enacting your care plan.

**Fellow:** A fellow is a licensed doctor with 3 or more years of experience who is now training in a specialized area of medicine. In our clinic, the fellows are training to be either general cardiologists or adult congenital heart disease specialists. They have already completed training in internal medicine or pediatrics and some have also completed general cardiology training.

**Healthcare professionals to support you in your care:** Registered nurses, medical assistants and administrative staff.

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When appropriate, we may also recommend evaluations and testing with the following services that our comprehensive program provides:

- **Electrophysiology:** doctors specializing in heart rhythm issues
- **Cardiac Surgeons**
- **Interventional Cardiologists:** cardiologist specializing in catheter-based procedures
- **Advanced Heart Failure and Transplantation Services**
- **Obstetric, Gynecological, and Advanced Prenatal Care**
- **Pulmonary and Sleep Medicine Services**
- **Hepatology Services:** doctors specializing in liver disorders
- **Cardiac Psychiatry**
- **Genetic Care and Counseling**
- **Social Work Support**
- **Diagnostic Testing and Imaging**

### *Which patients are seen in the ACHD Clinic?*

We see all patients born with heart disease. Some examples of the diagnoses we care for and manage are:

- Atrial Septal Defect
- Ventricular Septal Defect
- Atrioventricular Septal Defect
- Anomalous Coronary Arteries
- Anomalous Pulmonary Venous Return
- Bicuspid Aortic Valve
- Congenital Valvular Stenosis
- Congenital Valvular Regurgitation
- Coarctation of the Aorta
- Ebstein Anomaly
- Eisenmenger Syndrome
- Fontan Procedure
- Interrupted Aortic Arch
- Single Ventricle
- Tetralogy of Fallot
- Transposition of the Great Arteries
- Truncus Arteriosus
- Valve Atresia
- Vascular Ring/Aortic Arch Anomalies

### *How can the clinic help me?*

It is critical that your cardiologist has an in-depth understanding of your condition and experience taking care of patients like you. At other centers, general adult cardiologists may be unfamiliar with your condition and pediatric cardiologists may lack experience caring for adults. The University of Washington Adult Congenital Heart Program has a team of cardiologists, interventional cardiologists, surgeons and imagers with advanced training in adult congenital heart disease who have dedicated their careers to taking care of patients like you. Also, we care for women with congenital heart disease who are considering pregnancy and work with expert obstetricians with experience delivering women with complex cardiac needs.

### *What can I expect at my first clinic visit?*

Our nursing staff will welcome you and your family to the ACHD program with an overview of the program, direct contact information of our team, and provide education about you or your loved one's heart condition. Our ACHD Program is truly team-based. Depending on your condition you may have an ECG or an echocardiogram before your visit. You will be seen by a cardiology fellow and attending physician who discuss your condition, listen to your concerns and work with you to determine the best treatment plan.



### **How Do I Refer a Patient?**

To refer a patient or speak with any of the ACHD Clinic physicians, call **206.598.3734**; fax 206.598.7451

### ***Will I need follow-up visits?***

The vast majority of congenital heart disease patients need regular checkups with a congenital heart disease cardiologist at intervals ranging from every several months to every several years. In some cases we can “share care” with local doctors and alternate visits in some form. We work with patients to make sure the type and frequency of follow up visits meet their needs.

### ***Can I take part in a research study at the clinic?***

Our program is actively involved in numerous research efforts including studying cutting-edge procedures to allow for minimally invasive valve replacement. If you are eligible for a research study we will discuss options with you during your visit. In many cases we offer patients the opportunity to voluntarily participate in research studies of patient databases (“registries”). You will receive the same high medical care regardless of your decision to participate in a research study.

### ***Do I need a referral from my doctor to make an appointment?***

Depending on your health insurance plan you may need a referral or authorization from your primary care provider or health insurance plan. Please contact your insurance provider to find out if they require a referral or authorization. Our patient care coordinators can also help you find out if you need a referral or authorization.

### ***How do I Make an Appointment?***

The UW Medicine ACHD Clinic offers care at:

UWMC Regional Heart Center  
1959 NE Pacific Street, Seattle WA 98195

UW Medicine Regional Heart Center-Edmonds  
217012 76th Avenue West, Edmonds, WA 98026

UW Medicine Eastside Specialty Center  
1700 116th Avenue NE, Bellevue, WA 98004

Please call 206.598.3734; fax 206.598.7451 to schedule an appointment or inquire about outreach services.