



Adult Congenital Heart Disease (ACHD) Clinic Facts for Referring Providers

What is the University of Washington Adult Congenital Heart Disease (ACHD) Clinic?

The UW Medicine Adult Congenital Heart Disease Clinic, an Adult Congenital Heart Association (ACHA) ACHD Accredited Program is dedicated to providing comprehensive care for adults with congenital heart diseases: We have over 3,000 ACHD patient visits a year in our clinic. Our team is made of cardiologists, interventional cardiologists, electrophysiologists and surgeons all of whom have expertise in the care of adults with congenital heart disease. We are a collaborative, multi-disciplinary team who are available to accept patients for full transition of care and to partner with you in the community to care for patients together.

Over 1 million adults in the U.S. have congenital heart disease (CHD) which means there are more adults than children living with CHD. The success of pediatric cardiology and cardiac surgery has improved the survival of patients with CHD, which has created a growing need for ACHD physicians. These patients have conditions previously treated by pediatric cardiologists but as adults they require specialized cardiac care not typically found in adult medical practices.

The ACHD Program at UW Medicine Heart Institute and Seattle Children's Hospital has bridged the gap in care of this specialized patient population with a unique partnership utilizing the expertise found at both centers. This program helps adolescent patients transition into adult cardiology care and enables them to be seen at both locations.

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

Why is ACHD Care Important and What Conditions are Seen in ACHD Clinic?

Because of advances in pediatric heart surgery and pediatric cardiology, most children born with congenital heart disease (CHD) survive and there are now more adults than children living with CHD in the U.S. However, these patients are rarely “cured” and require a lifetime of follow-up care. Our team is made up of cardiologists and surgeons from the University of Washington and Seattle Children's who provide a comprehensive medical, diagnostic, and surgical center for ACHD patients. We are committed to helping our patients live long and healthy lives.

Example of Conditions seen in Clinic:

- Atrial Septal Defect
- Ventricular Septal Defect
- Atrioventricular Septal Defect
- Anomalous Coronary Arteries
- Anomalous Pulmonary Venous Return
- Bicuspid Aortic Valve
- Coarctation of Aorta
- Congenital Valvular Stenosis
- Congenital Valvular Regurgitation
- 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

What Should the Patient Expect Prior to and at the Visit?

All of our new patient ACHD referrals are reviewed within 48 hours by a physician to identify the timeframe in which the patient needs to be seen and if any new or additional testing will be needed at the time of the initial appointment. Our patient care coordinator (PCC) serves as a navigator to the patient and their family throughout the process. The PCC is the patient, family and referring provider's primary contact and will even obtain medical records and imaging on behalf of the patient sometimes as far back as 30 years.

ACHD nursing staff welcomes patients to the ACHD program with an overview of the program, direct contact information for the ACHD team, and education about the patient's heart condition. Patients are seen by a cardiology fellow and attending physician. Our patients receive follow up appointments with the fellow and ACHD attending physician or our nurse practitioner.

Are Follow Up Appointments Necessary?

The vast majority of ACHD patients need continued follow up visits with ACHD cardiologists, though in many cases we can “share care” with local cardiologists and/or primary care providers if that is best for the patient. The team works to find a frequency and type of follow-up that meets the patients' needs.

Are Patients Enrolled in or Offered Participation in Research Studies?

Research is essential to improving patient care, and we collaborate locally, nationally and internationally to offer patients opportunities to enroll in clinical and translational research studies in many areas. Participation in voluntary and medical care will be unaffected by a patient's decision to not participate.



What Other Services are Offered for ACHD Patients?

- Adult congenital heart surgery (over 100 surgeries performed at UW each year)
- Transcatheter pulmonic and aortic valve replacement, valve-in-valve procedures, transcatheter treatment of atrial septal defects, ventricular septal defects, patent ductus arteriosus (PDA), coarctation of the aorta, baffle obstruction, baffle leaks and other complex congenital interventions
- Cardiac MRI, CT, and transesophageal echocardiography
- 3D printing of hearts to aid in surgical planning
- ACHD electrophysiology
- ACHD transplantation evaluation and mechanical circulatory support
- Cardiac anesthesia
- Multidisciplinary case conference to discuss all ACHD patients undergoing cardiac surgery and complex interventional procedures
- Obstetric, gynecological, and advanced prenatal care
- Pulmonary and Sleep Medicine consultation and diagnostic services
- Hepatology services
- Cardiac psychiatric services
- Cardiac genetics care and counseling
- Social Work support
- Neurocognitive testing

Who Can the Patients Expect to See in ACHD Clinic?

Our comprehensive program, including providers from UW Medicine and Seattle Children's Hospital are trained in adult congenital heart disease and lead a team that provides effective, high quality care for this unique patient population. The ACHD team includes:

Cardiologists:

Eric Krieger, MD
Karen Stout, MD
Jason Deen, MD
Yonatan Buber, MD
Zachary Steinberg, MD

Electrophysiologists:

Stephen Seslar, MD
Melissa Robinson, MD

Interventional Cardiologists:

Thomas Jones, MD
Brian Morray, MD
Zachary Steinberg, MD

Cardiac Surgeons:

Edward Verrier, MD
Daniel Zimpfer, MD
Francisco Gensini, MD
Christopher Burke, MD

Advanced Heart Failure/Transplantation

April Stempien-Otero, MD
Elina Minami, MD

ACHD ARNP

Elizabeth Bayley, ARNP
Jaimie Pechan, ARNP

Other Healthcare Professionals:

Brenda O'Connell BSN, RN
Ame Dohm, MSN, RN
Jessica Branco King, RN
Cyndi DeVine, Patient Care Coordinator
Dee Narvaez, Patient Service Specialist
Jilian Angiulo Program Operations Specialist



ACHD Services are Available at:

UW Medicine Heart Institute
1959 NE Pacific Street, Seattle WA 98195
206.598.3734; fax 206.598.7451

UW Medicine Heart Institute Edmonds
217012 76th Avenue West,
Edmonds, WA 98026
206.598.3734; fax 206.598.7451

Inquire about ACHD outreach services at 206.598.1764