

General Program Information

Please be prepared to complete the survey in one session. Once you exit or close the survey, you can go back and change existing responses but the survey cannot be left incomplete. Data will only be uploaded into the online Clinic Directory if the survey is completed in full.

Please contact clinicdirectory@achaheart.org if you have any questions or need further assistance. Thank you.

1. Name of ACHD Program (this is not the name of the hospital/university that houses the program).

2. Year the program was formalized (when half-day sessions were instituted).

3. Street address of Clinic (i.e. location where patients go for visits)

Address:

Address 2:

City:

State/Province:

ZIP/Postal Code:

4. Please provide a mailing address as ACHA may periodically send updated programmatic information through the USPS.

Address:

Address 2:

City:

State/Province:

ZIP/Postal Code:

5. ACHD Program Website URL. If none, please indicate N/A.

6. Telephone Number for Patient Inquiries

Phone Number:

7. Telephone Number for Appointment Requests

Phone Number:

8. After Hours Telephone Number

Phone Number:

9. Email address for Patient Inquiries

Email Address:

10. Do you have a 24/7 ACHD on-call procedure in place?

Yes

No

11. Please provide the name and contact information for the person responsible for ordering and receiving ACHA materials and announcements.

Name

Title

Email

Telephone Number

12. Please provide the name and contact information for the person responsible for paying professional membership dues.

Name

Title

Email

Telephone Number

13. Please provide the name and contact information for the person responsible for sponsorship opportunities.

Name

Title

Email

Telephone Number

Program Affiliations

Please indicate up to 3 hospital affiliations and medical school affiliation with your ACHD program.

14. Hospital Affiliation #1

15. Is the hospital:

- Adult Hospital
- Pediatric Hospital
- Adult/Pediatric Hospital

16. Hospital Affiliation #2

17. Is the hospital:

- Adult Hospital
- Pediatric Hospital
- Adult/Pediatric Hospital

18. Hospital Affiliation #3

19. Is the hospital:

- Adult Hospital
- Pediatric Hospital
- Adult/Pediatric Hospital

20. Medical School Affiliation

Care Setting

21. Number of half-day ACHD Clinic Sessions per week.

EXAMPLE 1: Doctors A & B both see patients for a half day on day 1 and only Doctor B sees patients for a half day on day 2. $(2*1) + (1*1) = 3$ HALF DAY SESSIONS

EXAMPLE 2: Doctor and CCA each have a full panel of patients for a half day on day 1 = 2 HALF DAY SESSIONS

EXAMPLE 3: Doctor sees a panel of patients assisted by CCA = 1 HALF DAY SESSION

EXAMPLE 4: Doctor double books and half are seen by CCA = 2 HALF DAY SESSIONS

EXAMPLE 5: Attending staff two fellows with full clinics = 2 HALF DAY SESSIONS

22. Outpatients are seen at which hospital (s)? (Please write out full name of hospital).

Hospital 1

Hospital 2

23. Do you have providers who see patients in both pediatric and adult settings?

Yes

No

24. Do you perform invasive cardiac procedures on ACHD patients at your institution?

Yes

No

25. Where are catheter-based procedures done?

- Adult hospital
- Pediatric hospital
- Adult/Pediatric hospital
- Referred Elsewhere

26. Where are invasive EP procedures done?

- Adult hospital
- Pediatric hospital
- Adult/Pediatric hospital
- Referred Elsewhere

27. Where are ACHD surgeries done?

- Adult hospital
- Pediatric hospital
- Adult/Pediatric hospital
- Referred Elsewhere

28. Do you have established referral relationships with other ACHD programs for needed consultation, procedures or second opinions?

- Yes
- No

29. Is there a formal* transition program between pediatric and ACHD clinics?

*The questions seek the existence of intentional transition programs beginning in early or mid-adolescence in pediatric cardiology preparing patients and families for the eventual move to an ACHD program/environment. This is not a commitment to transfer at a certain age, rather an educational process taking place distinct from office visits and a process occurring over months to years.

- Yes
- No

30. If yes, initial transition visits commence at what age?

31. If yes, do you have specific transition visits scheduled separately from usual medical visits?

- Yes
 No

32. If no, do you have transition education done during usual medical visits?

- Yes
 No

33. Is there a regularly scheduled patient care conference?

- Yes
 No

34. If yes, how often?

- Weekly
 1-3 times per month
 less than 1 time per month

35. If no, is there an ad hoc conference when needed?

- Yes
 No

36. Does your program provide local ACHD specific patient/family support or educational meetings at least quarterly or have an ongoing relationship with a local ACHD specific support/educational group outside of your program?

Yes

No

Medical Program Director

Please note the Medical/Program Director's full contact information (email address, phone number and mailing address) are for internal purposes only. Only name, credentials and board certifications will be listed online.

37. Medical Director

Name:

Credentials:

Mailing Address:

Address 2:

City:

State/Province:

ZIP/Postal Code:

Country:

Email Address:

Phone Number:

38. Medical Director is a paid ACHA medical professional member

*Medical Professional Membership allows ACHA to continue to fulfill its mission

Yes

No

39. Medical Director is Board Certified In:

Please choose all that apply.

- Internal Medicine
- IM Cardiology
- Pediatrics
- Ped Cardiology
- ACHD
- ACHD Board Eligible
- Other - please note certification in comment box below

Comments

40. Does the Medical Director have formal* training in ACHD?

Formal training may include a formal ACHD rotation, individualized long-term mentoring/informal ACHD fellowship; or formal ACHD fellowship (1 or 2 years).

- Yes
- No

41. If yes, was the Medical Director's ACHD training:

- Less than 1 year
- 1 year
- More than 1 year

42. If no, how did the Medical Director gain expertise in ACHD?

43. Years that Medical Director has been involved in ACHD care

44. % of Medical Director's time devoted to the ACHD Program

45. Does your ACHA clinic have a designated Medical Co-Director?

Yes

No

Medical Program Co-Director

Please note the Co-Director's full contact information (email address, phone number and mailing address) are for internal purposes only. Only name, credentials and board certifications will be listed online.

46. Medical Co-Director

Name:

Credentials:

Mailing Address:

Address 2:

City:

State/Province:

ZIP/Postal Code:

Country:

Email Address:

Phone Number:

47. Medical Co-Director is a paid ACHA medical professional member

*Medical Professional Membership allows ACHA to continue to fulfill its mission

Yes

No

48. Medical Co-Director is Board Certified In:

Please choose all that apply.

- Internal Medicine
- IM Cardiology
- Pediatrics
- Ped Cardiology
- ACHD
- ACHD Board Eligible
- Other - please note certification in comment box below

Comments

49. Does Medical Co-Director have formal* training in ACHD?

Formal training may include a formal ACHD rotation, individualized long-term mentoring/informal ACHD fellowship; or formal ACHD fellowship (1 or 2 years).

- Yes
- No

50. If yes, was Medical Co-Director's ACHD training:

- Less than 1 year
- 1 year
- More than 1 year

51. If no, how did Medical Co-Director gain expertise in ACHD?

52. Years Medical Co-Director has been involved in ACHD care

53. % of Medical Co-Director's time devoted to the ACHD Program

Administrative Program Director, Program Manager or Program Administrative Manager

If you have an Administrative Program Director, Program Manager or Program Administrative Manager, please note the full contact information below (email address, phone number and mailing address). This is for internal purposes only. Only name, credentials and board certifications will be listed online.

54. Do you have a designated Administrative Program Director, Program Manager or Program Administrative Coordinator in your clinic?

Yes

No

55. Administrative Program Director, Program Manager or Program Administrative Manager

Name:

Credentials:

Mailing Address:

Address 2:

City:

State/Province:

ZIP/Postal Code:

Country:

Email Address:

Phone Number:

56. Administrative Program Director, Program Manager or Program Administrative Coordinator is a paid ACHA medical professional member

*Medical Professional Membership allows ACHA to continue to fulfill its mission

Yes

No

Clinic Staffing

57. Total Number of (additional) Cardiologists who attend ACHD Clinics.

This includes those EP, interventional or HF physicians with specific ACHD training or experience who dedicate a significant portion of their effort to ACHD.

Do not include Director/Co-Director in this total. Additionally, do not include the many interventionalists, electrophysiologists, HF doctors, etc. who ably assist the ACHD program but have no focused commitment to ACHD in their own practice.

58.

List attendings below.

Additional Cardiologist. Include Name, Credentials, Board Certified in (Int Med; IM Card; Peds; Ped Card; ACHD; ACHD Board Eligible), Email Address and Phone Number.

Name:

Credentials:

Board Certified:

Email Address:

Phone Number:

59. Additional Cardiologist. Include Name, Credentials, Board Certified in (Int Med; IM Card; Peds; Ped Card; ACHD; ACHD Board Eligible), Email Address and Phone Number.

Name:

Credentials:

Board Certified:

Email Address:

Phone Number:

60. Additional Cardiologist. Include Name, Credentials, Board Certified in (Int Med; IM Card; Peds; Ped Card; ACHD; ACHD Board Eligible), Email Address and Phone Number.

Name:

Credentials:

Board Certified:

Email Address:

Phone Number:

61. Additional Cardiologist. Include Name, Credentials, Board Certified in (Int Med; IM Card; Peds; Ped Card; ACHD; ACHD Board Eligible), Email Address and Phone Number.

Name:

Credentials:

Board Certified:

Email Address:

Phone Number:

62. Additional Cardiologist. Include Name, Credentials, Board Certified in (Int Med; IM Card; Peds; Ped Card; ACHD; ACHD Board Eligible), Email Address and Phone Number.

Name:

Credentials:

Board Certified:

Email Address:

Phone Number:

63. Does your program include a Cardiac Care Associate [Nurse Practitioner(s)/Physician Assistant(s)/Registered Nurse(s)]?

Yes

No

64. CCA. Include Name, Credentials, Title, Email Address and Phone Number.

Name:

Credentials:

Title:

Email Address:

Phone Number:

65. CCA. Include Name, Credentials, Title, Email Address and Phone Number.

Name:

Credentials:

Title:

Email Address:

Phone Number:

66. CCA. Include Name, Credentials, Title, Email Address and Phone Number.

Name:

Credentials:

Title:

Email Address:

Phone Number:

67. CCA. Include Name, Credentials, Title, Email Address and Phone Number.

Name:

Credentials:

Title:

Email Address:

Phone Number:

68. Does your program include a social worker and/or psychologist?

Yes

No

69. Social worker or psychologist, Include Name, Credentials, Title, Email Address and Phone Number

Name:

Credentials:

Title:

Email Address:

Phone Number:

70. Social worker or psychologist, Include Name, Credentials, Title, Email Address and Phone Number

Name:

Credentials:

Title:

Email Address:

Phone Number:

71. Does your program include other staff, such as an office manager, transition coordinator, outreach manager, patient liaison etc?

Yes

No

72. If yes to other staff, please list them here.

Name:

Credentials:

Title:

Email Address:

Phone Number:

73. If yes to other staff, please list them here.

Name:

Credentials:

Title:

Email Address:

Phone Number:

74. If yes to other staff, please list them here.

Name:

Credentials:

Title:

Email Address:

Phone Number:

75. If yes to other staff, please list them here.

Name:

Credentials:

Title:

Email Address:

Phone Number:

Clinical Services Offered

Does your program offer:

76. ACHD-experienced Diagnostic Catheterization

Yes

No

77. ACHD-experienced Interventional Catheterization

Yes

No

78. ACHD-experienced Diagnostic Electrophysiology

Yes

No

79. ACHD-experienced Interventional Electrophysiology

Yes

No

80. ACHD-experienced Cardiac MRI

Yes

No

81. ACHD-experienced Multi-Slice Cardiac CT

Yes

No

Additional ACHD-Experienced Consultive and Support Services

Does your program offer:

82. ACHD-experienced high risk obstetrics/perinatology

Yes

No

83. Contraceptive counseling with knowledge of appropriate contraception for ACHD patient

Yes

No

84. Geneticist/genetic counseling

Yes

No

85. Cardiac rehabilitation services

Yes

No

86. Financial/medical insurance counselors

Yes

No

87. Psychologist/psychiatrist

Yes

No

88. Medical Social Worker

Yes

No

89. Pulmonary arterial hypertension (PAH) in ACHD is evaluated:

Please choose one answer.

Within our ACHD program

In collaboration with our pulmonary hypertension specialists

By pulmonary hypertension specialists to whom we refer at suitable institutions

90. Pulmonary arterial hypertension (PAH) in ACHD is managed medically:

Please choose one answer.

Within our ACHD program

In collaboration with our pulmonary hypertension specialists

By pulmonary hypertension specialists to whom we refer at suitable institutions

91. When lung transplant is considered in our ACHD patients with PAH, they are:

Please choose one answer.

Typically transplanted within our own institution

Referred to a suitable lung transplant program

Surgical and Interventional Resources

NOTE: Data regarding numbers of annual patient visits and procedures are noted as “self reported”.

92. Total Number of Patient Visits to ACHD Clinic in 2016. Please count only ACHD patients.

PLEASE NOTE: Report only total ACHD patient visits to ACHD clinic in the single year 2016. Do not report total ACHD patient population in multi-year database. Do not report here ACHD patients seen outside your designated ACHD clinic (such as non-ACHD cardiology clinics, surgical clinics).

93. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

94. Total number of Pediatric (<18 y.o.) CHD operations performed at your institution(s) in 2016

95. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

96. Total number of Adult (>18 y.o.) CHD operations performed at your institution(s) in 2016

97. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

98. Total number of cardiologists performing interventional catheterizations

99. Total number of surgeons performing more than 75 CHD or ACHD operations annually

Training and Research

100. Do you have an ACHD training program for fellows?

This includes advanced fellowship training or rotations for pediatric and adult general cardiology fellows.

Yes

No

101. If yes, indicate all that apply:

Formal ACHD rotation for general cardiology fellows (in Peds)

Formal ACHD rotation for general cardiology fellows (in Adult)

Individualized long-term mentoring (or informal ACHD fellowship)

Formal dedicated ACHD fellowship (1 year)

Formal dedicated ACHD fellowship (2 year)

102. If you have formal additional ACHD fellowship training (1 or 2 years), can fellows outside your institution apply for a position?

Yes

No

Not Applicable

103. Does your program undertake ACHD research?

Yes

No

104. If yes, do you participate in multicenter research?

Yes

No

105. Year of program's most recent receipt of external funding. If not applicable, please indicate N/A.

106. Year of program's last publication. If not applicable, please indicate N/A.

Miscellaneous Clinical and Demographic Data

The questions on this page are for the purpose of data collection and reporting for funding for ACHA. Your answers are very important to us and we appreciate your time in answering them.

107. Total number of ACHD patients with PAH seen in 2016

108. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

109. Total number of patients with heart valve disease as the primary defect seen in 2016

110. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

111. Number of low income patients (below the poverty level) seen in 2016 (best guess or estimate if data not collected) or note unknown

112. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

113. Number of uninsured patients seen in 2016

114. Data obtained from:

- Database. Please tell us which database you use in the Comment field.
- Estimate
- Business Office

Comment

115. Top five co-morbidities seen in your program in 2016

1.
2.
3.
4.
5.

116. Top 5 CHDs seen in your program in 2016

1.

2.

3.

4.

5.

117. Suggestions for ACHA Patient/Family Webinar Topics

1.

2.

3.

4.

5.

Director's Description of the Program

Briefly describe special expertise within or unique features of your program. Information to include may be referral programs, satellite locations that see ACHD patients, unique services, etc.

118. Description

119. Please provide contact information of person completing survey.

Name:

Title:

Email Address:

Phone Number: