

Fontan Exercise Survey

Who is completing this survey?

- Parent / guardian of Fontan patient
 Fontan patient
-

What is the Fontan patient's current age (in years)?

Individuals with a Fontan circulation can have difficulties with energy level during activity. In recent years more research has shown the benefit of physical activity in patients with a Fontan circulation including increased energy and ability to participate in physical activity among other benefits. The findings from these research studies is becoming better understood by pediatric cardiologists but may not be reaching individuals with a Fontan circulation. With this survey we hope to better understand the discussions patients have with their cardiologists about physical activity, time spent in physical activity, level of physical activity participated in, and concerns individuals with a Fontan circulation have about participating in physical activity. We invite you/your child to participate in a survey research project to help learn more about exercise among people with a Fontan circulation. This brief, one-time survey should take less than 15 minutes to complete. We appreciate your/your child's participation.

Your/your child's participation is completely voluntary. Participation is not required. All information will be kept strictly confidential. No link from the survey to you/your child will be made. The survey is anonymous. The results of the survey will be kept indefinitely for use in future studies.

If you/your child agree to complete the questionnaire, read the following statement of consent, and click on the "Start survey" button below which will send you to the web-based survey. Thank you for your help with this project.

I have read the information given above. I understand the meaning of this information. I consent/assent to participate in the project. I am completing this survey, and I am a person who has a Fontan circulation, or I am the parent/guardian of a child who has a Fontan circulation.

If you are less than 15 years old, please have a parent assist you with this survey. If you are between 15-18 years old, please only participate after getting permission from your parent/guardian.

Start Survey I do not Consent / Assent

Is your parent / guardian aware you are taking this survey (and available to assist you if needed, if under age 15)?

- Yes
 No
-

If under age 18, your parent / guardian must be aware you are taking this survey (and be available to answer any questions you might have, if under age 15).

What is your child's current age in months (0-36)?

What is your child's sex?

Male Female

What was your child's age when he/she had Fontan surgery (in closest half-year, for example 2, 2.5, 3, etc.)?

Where does your child currently receive heart care?

United States or US territories
 Other country

Which country?

Which state or territory?

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- District of Columbia
- Puerto Rico
- Guam
- Northern Marianas
- US Virgin Islands
- American Samoa

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Where does your child receive his/her routine heart checkups?

- A clinic or office that belongs to a hospital that does child heart surgeries
 - A clinic or office that does not belong to a hospital that does child heart surgeries
-

How often is your child seen by his/her main cardiologist?

- Less than every other year
 - Every other year
 - Once a year
 - More than once a year
-

Some children that have had a Fontan operation are seen regularly by their pediatric cardiologist and are additionally seen by a separate cardiology clinic dedicated specifically to the follow up of patients with a Fontan circulation where they see providers from multiple specialties such as a liver doctor, kidney doctor, and/or a lung doctor in addition to the heart doctor. These clinics are sometimes referred to as a Single Ventricle Clinic, Single Ventricle Program, or Fontan clinic. In addition to your child's regular pediatric cardiologist is your child also seen in a clinic dedicated to follow up of patients with a Fontan circulation?

- Yes
 - No
-

How frequently is your child seen in the separate Fontan clinic?

- One time only
- Less than every other year
- Every other year
- Once a year
- More than once a year

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Does your child have ongoing problems with his/her muscles, joints, or bones? Yes No

Do these problems limit his/her activity? Yes No

Does your child have neurologic problems such as seizures, cerebral palsy, or spasticity? Yes No

Do these problems limit his/her activity? Yes No

Has your child been diagnosed with a respiratory problem such as asthma, tracheostomy, or ventilator dependence? Yes No

Does this problem limit his/her activity? Yes No

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Is gym class offered as part of your child's schooling?

Yes No

How much does your child participate in gym class at school? (Some people with a Fontan operation are told by their cardiologist that they can participate in gym class but should be able to limit themselves as needed. If this is what your child's cardiologist has told you then answer with how much your child is able to participate.)

- Fully participates
 Participates but occasionally has to limit himself/herself
 Does not participate
-

What is your child's limited participation due to?

- S/he does not have enough energy to participate in the activity
 S/he has symptoms with physical activity (lightheaded, dizzy, blurry vision, chest pain, palpitations, and/or passes out)
 Limitations not related to his/her heart
 S/he does not have any limitations in his/her energy and does not have any symptoms with activity but is partially restricted by his/her cardiologist
 S/he does not have any limitations in his/her energy and does not have any symptoms with activity but is partially restricted by his/her parents or guardians
-

Why does your child not participate?

- S/he does not have enough energy to participate in the activity
 S/he has symptoms with physical activity (lightheaded, dizzy, blurry vision, chest pain, palpitations, and/or passes out)
 Limitations not related to his/her heart
 S/he does not have any limitations in his/her energy and does not have any symptoms with activity but is restricted by his/her cardiologist
 S/he does not have any limitations in his/her energy and does not have any symptoms with activity but is restricted by his/her parents or guardians
-

Does your child participate in organized sports?

Yes No

Please check the organized sports in which your child participates.

- Football
 - Basketball
 - Baseball
 - Softball
 - Soccer
 - Volleyball
 - Tennis
 - Track
 - Boxing
 - Canoeing / rowing
 - Cycling
 - Ice hockey
 - Field hockey
 - Lacrosse
 - Swimming
 - Fencing
 - Rugby
 - Skating
 - Wrestling
 - Golf
 - Gymnastics
 - Martial arts
 - Equestrian
 - Bowling
 - Cheer
 - Other
- (Select all that apply)

In what other organized sport does your child participate?

The following questions refer to how much time your child spends engaged in low energy activities such as going for a walk or leisurely riding his/her bike. Do not include time spent in more high energy or strenuous activities..

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

How many days per week does your child spend greater than 30 continuous minutes engaged in activities such as going for a walk or leisurely riding his/her bike?

0 1 2 3 4 5 6 7

How many days per week does your child engage in activities such as going for a walk or leisurely riding his/her bike for less than 30 continuous minutes but more than 0 minutes?

0 1 2 3 4 5 6 7

How many total hours does your child spend per week engaged in activities such as going for a walk or leisurely riding his/her bike?

- None to less than 1 hour
- 1 hour to less than 3 hours
- 3 hours to less than 5 hours
- 5 hours to less than 10 hours
- 10 hours or greater

The following questions refer to how much time your child spends engaged in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing. For younger children this could also include running around the house, yard, etc. Do not include time spent participating in activities that require less exertion.

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

How many days per week does your child spend greater than 30 continuous minutes engaged in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing?

0 1 2 3 4 5 6 7

How many days per week does your child engage in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing for less than 30 continuous minutes but more than 0 minutes?

0 1 2 3 4 5 6 7

How many total hours does your child spend per week engaged in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing?

- None to less than 1 hour
- 1 hour to less than 3 hours
- 3 hours to less than 5 hours
- 5 hours to less than 10 hours
- 10 hours or greater

 Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Do you ever limit your child's participation in physical activities because of his or her heart condition? Yes No

What type(s) of sports or activities? Contact sports
 Heavy weight lifting
 Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
 Competitive sports
 All activity
 (Select all that apply)

Why is your child's participation in contact sports limited? Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of his/her heart condition
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
 He/she is limited by conditions other than his/her heart

What are your concerns in regards to contact sports? Concern that something bad could happen to him/her while engaged in the activity
 Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
 (Select all that apply)

Why is your child's participation in heavy weight lifting limited? Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of his/her heart condition
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
 He/she is limited by conditions other than his/her heart

What are your concerns in regards to heavy weight lifting? Concern that something bad could happen to him/her while engaged in the activity
 Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
 (Select all that apply)

Why is your child's participation in intense aerobic activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of his/her heart condition
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
- He/she is limited by conditions other than his/her heart

What are your concerns in regards to intense aerobic activity?

- Concern that something bad could happen to him/her while engaged in the activity
 - Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
- (Select all that apply)

Why is your child's participation in competitive sports limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of his/her heart condition
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
- He/she is limited by conditions other than his/her heart

What are your concerns in regards to competitive sports?

- Concern that something bad could happen to him/her while engaged in the activity
 - Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
- (Select all that apply)

Why is your child's participation in all activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of his/her heart condition
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
- He/she is limited by conditions other than his/her heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to him/her while engaged in the activity
 - Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
- (Select all that apply)

 Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Are there activities that your child would like to participate in but does not due to his or her medical condition?

Yes No

What type(s) of sports or activities?

- Contact sports
 Heavy weight lifting
 Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
 Competitive sports
 All activity
 (Select all that apply)

Why is your child's participation in contact sports limited?

- Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of his/her heart condition
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
 He/she is limited by conditions other than his/her heart

What are your concerns in regards to contact sports?

- Concern that something bad could happen to him/her while engaged in the activity
 Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
 (Select all that apply)

Why is your child's participation in heavy weight lifting limited?

- Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of his/her heart condition
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
 He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
 He/she is limited by conditions other than his/her heart

What are your concerns in regard to heavy weight lifting?

- Concern that something bad could happen to him/her while engaged in the activity
 Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
 (Select all that apply)

Why is your child's participation in intense aerobic activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of his/her heart condition
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
- He/she is limited by conditions other than his/her heart

What are your concerns in regard to intense aerobic activity?

- Concern that something bad could happen to him/her while engaged in the activity
 - Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
- (Select all that apply)

Why is your child's participation in competitive sports limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of his/her heart condition
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
- He/she is limited by conditions other than his/her heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to him/her while engaged in the activity
 - Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
- (Select all that apply)

Why is your child's participation in all activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of his/her heart condition
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her cardiologist
- He/she could participate (good energy and no symptoms with the activity) but is restricted by his/her parents and/or guardian
- He/she is limited by conditions other than his/her heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to him/her while engaged in the activity
 - Concern that it would be harmful/unhealthy for him/her to participate in the activity on a frequent basis
- (Select all that apply)

 Missed Question(s)

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 Child's Cardiologist Recommendations

How often does your child's cardiologist discuss activity recommendations or restrictions with you?

- Never
 Some clinic visits
 Most clinic visits
 All clinic visits
-

Does your child's cardiologist discuss specific activities or exercises that s/he recommends? Examples could include recommending specific physical activities such as soccer or bike riding or specific exercises such as leg strengthening routines.

- Yes No
-

Are there specific activities that s/he restricts?

- Yes No
-

What type(s) of sports or activities does s/he restrict?

- Contact sports
 Heavy weight lifting
 Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
 Competitive sports
 All activity
 (Check all that apply)
-

Does s/he give specific goals for time spent in activity? Examples could include recommending that your child participates in activity for at least an hour at a time or recommending overall activity goals of 60 minutes per day for at least four days per week.

- Yes No
-

Does s/he give specific goals for intensity of activity? Examples could include recommending running on a treadmill with a goal speed, riding an elliptical or stationary bike with a goal RPM, or participating in activity with the goal of increasing heart rate to a certain goal or until sweating.

- Yes No
-

 Single Ventricle Clinic Cardiologist Recommendations

How often does the cardiologist that your child sees in the single ventricle clinic discuss activity recommendations or restrictions with you?

- Never
 Some clinic visits
 Most clinic visits
 All clinic visits
-

Does s/he discuss specific activities or exercises that s/he recommends? Examples could include recommending specific physical activities such as soccer or bike riding or specific exercises such as leg strengthening routines.

- Yes No
-

Are there specific activities that s/he restricts? Yes No

What type(s) of sports or activities does s/he restrict?

- Contact sports
- Heavy weight lifting
- Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
- Competitive sports
- All activity

(Select all that apply)

Does s/he give specific goals for time spent in activity? Examples could include recommending that your child participates in activity for at least an hour at a time or recommending overall activity goals of 60 minutes per day for at least four days per week. Yes No

Does s/he give specific goals for intensity of activity? Examples could include recommending running on a treadmill with a goal speed, riding an elliptical or stationary bike with a goal RPM, or participating in activity with the goal of increasing heart rate to a certain goal or until sweating. Yes No

Missed Question(s)

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How important do you think physical activity is to your child's health and quality of life?

- Not important at all
 - Somewhat important
 - Important
 - Very important
 - Extremely important
-

How important does your child think physical activity is to his/her health and quality of life?

- Not important at all
 - Somewhat important
 - Important
 - Very important
 - Extremely important
-

How interested is your child in physical activity?

- Not interested at all
 - Somewhat interested
 - Interested
 - Very interested
 - Extremely interested
-

Do you feel like your child's cardiologist's recommendations regarding physical activity are:

- Much too restrictive
- A little too restrictive
- Just right
- A little too lenient
- Much too lenient

To what extent do each of the following factors limit your child's activity beyond the restrictions recommended by his or her cardiologist?

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	Significantly	Moderately	Somewhat	Very little	Not at all
My child does not have enough energy to participate in the activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child has symptoms with physical activity (lightheaded, dizzy, blurry vision, chest pain, palpitations, and/or passes out)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The child is not interested in physical activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern from parents or guardians that the activity is not safe for the child because of his/her heart condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern from the child that the activity is not safe for him/her because of his/her heart condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For various reasons, some patients choose to participate in activities against the recommendations of their cardiologist. Do you allow your child to participate in activities that the cardiologist recommends against?

Yes No

Why?

Belief that your child can participate without increased risk

Belief that while there is increased risk involved with the activity, the benefits of the activity outweigh the increased risk.

What benefits do you believe exist in participating in the restricted activities?

Improved physical fitness

Weight loss

Improvement in energy

Improvement in child's mood and/or decrease in stress, anxiety, or depression

Decreased risk of chronic health conditions such as high blood pressure, high cholesterol, and diabetes

Social interaction with other kids his/her age (Select all that apply)

 Missed Question(s)

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Over the past few years have the recommendations from your child's pediatric cardiologist changed regarding physical activity?

Yes No

What recommendations has your child's pediatric cardiologist started making regarding physical activity?

- My child's pediatric cardiologist started recommending specific activities or exercises. Examples could include recommending specific physical activities such as soccer or bike riding or specific exercises such as leg strengthening routines
 - My child's pediatric cardiologist started discussing the benefits of physical activity but has not recommended specific activities or exercises
 - My child's pediatric cardiologist started limiting my child's participation in physical activity
-

What reason does your child's pediatric cardiologist give for the new recommendations?

- Benefit of physical activity for patients with a Fontan operation
 - Benefit of physical activity for general health, but not specific to having had a Fontan operation
 - Concern for recent changes in my child's heart that may make physical activity dangerous for him/her
 - My child's pediatric cardiologist did not give a reason for the new recommendations
 - Other
-

What other reason does your child's pediatric cardiologist give for the new recommendations?

Has your child changed his/her physical activity level based on these changed recommendations from his/her pediatric cardiologist?

Yes No

What changes has your child made to his/her physical activity level based on the recommendations of his/her pediatric cardiologist?

- My child has started participating in organized sports
 - My child has started a specific workout routine such as lower extremity weight training at the gym
 - My child has started participating in or increased his/her participation in active but not strenuous activities such as going for a walk or leisurely riding his/her bike
 - My child has started participating in or increased his/her participation in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing
 - My child has stopped participating in organized sports
 - My child has stopped participating in a specific workout routine such as lower extremity weight training at the gym
 - My child has decreased or stopped his/her participation in low energy activities such as going for a walk or leisurely riding his/her bike
 - My child has decreased or stopped his/her participation in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing
- (Select all that apply)

Missed Question(s)

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What is your sex?

Male Female

What was your age when you had Fontan surgery (in closest half-year, for example 2, 2.5, 3, etc.)?

Where do you currently receive heart care?

United States or US territories
 Other country

Which country?

Which state or territory?

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- District of Columbia
- Puerto Rico
- Guam
- Northern Marianas
- US Virgin Islands
- American Samoa

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Where do you receive your routine heart checkups?

- A clinic or office that belongs to a hospital that does child heart surgeries
 - A clinic or office that does not belong to a hospital that does child heart surgeries
-

How often are you seen by your main cardiologist?

- Less than every other year
 - Every other year
 - Once a year
 - More than once a year
-

Some patients that have had a Fontan operation are seen regularly by their pediatric cardiologist and are additionally seen by a separate cardiology clinic dedicated specifically to the follow up of patients with a Fontan circulation where they see providers from multiple specialties such as a liver doctor, kidney doctor, and/or a lung doctor in addition to the heart doctor. These clinics are sometimes referred to as a Single Ventricle Clinic, Single Ventricle Program, or Fontan clinic. In addition to your regular pediatric cardiologist are you also seen in a clinic dedicated to follow up of patients with a Fontan circulation?

- Yes
 - No
-

How frequently are you seen in the separate Fontan clinic?

- One time only
- Less than every other year
- Every other year
- Once a year
- More than once a year

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Do you have ongoing problems with your muscles, joints, or bones? Yes No

Do these problems limit your activity? Yes No

Do you have neurologic problems such as seizures, cerebral palsy, or spasticity? Yes No

Do these problems limit your activity? Yes No

Have you been diagnosed with a respiratory problem such as asthma, tracheostomy, or ventilator dependence? Yes No

Do these problems limit your activity? Yes No

 Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Are you enrolled in school? Yes No

Is gym class offered as part of your schooling? Yes No

How much do you participate in gym class at school?
(Some people with a Fontan operation are told by their cardiologist that they can participate in gym class but should be able to limit themselves as needed. If this is what your cardiologist has told you then answer with how much you are able to participate.)

Fully participate
 Participate but occasionally have to limit yourself
 Do not participate

What is your limited participation due to?

Do not have enough energy to participate in the activity
 Have symptoms with physical activity (lightheaded, dizzy, blurry vision, chest pain, palpitations, and/or passes out)
 Limitations not related to your heart
 Do not have any limitations in your energy and do not have any symptoms with activity but you're partially restricted by your cardiologist
 Do not have any limitations in your energy and do not have any symptoms with activity but you're partially restricted by your parents or guardians
 (Select all that apply)

Why do you not participate?

Do not have enough energy to participate in the activity
 Have symptoms with physical activity (lightheaded, dizzy, blurry vision, chest pain, palpitations, and/or passes out)
 Limitations not related to your heart
 Do not have any limitations in your energy and do not have any symptoms with activity but you're restricted by your cardiologist
 Do not have any limitations in your energy and do not have any symptoms with activity but you're restricted by your parents or guardians
 (Select all that apply)

Do you participate in organized sports? Yes No

Please check the organized sports in which you participate.

- Football
 - Basketball
 - Baseball
 - Softball
 - Soccer
 - Volleyball
 - Tennis
 - Track
 - Boxing
 - Canoeing / rowing
 - Cycling
 - Ice hockey
 - Field hockey
 - Lacrosse
 - Swimming
 - Fencing
 - Rugby
 - Skating
 - Wrestling
 - Golf
 - Gymnastics
 - Martial arts
 - Equestrian
 - Bowling
 - Cheer
 - Other
- (Select all that apply)

In what other organized sport do you participate?

The following questions refer to how much time you spend engaged in low energy activities such as going for a walk or leisurely riding your bike. Do not include time spent in more high energy or strenuous activities..

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

How many days per week do you spend greater than 30 continuous minutes engaged in activities such as going for a walk or leisurely riding your bike?

0 1 2 3 4 5 6 7

How many days per week do you engage in activities such as going for a walk or leisurely riding your bike for less than 30 continuous minutes but more than 0 minutes?

0 1 2 3 4 5 6 7

How many total hours do you spend per week engaged in activities such as going for a walk or leisurely riding your bike?

- None to less than 1 hour
- 1 hour to less than 3 hours
- 3 hours to less than 5 hours
- 5 hours to less than 10 hours
- 10 hours or greater

The following questions refer to how much time you spend engaged in activities that involve higher levels or exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing. Do not include time spent participating in activities that require less exertion.

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

How many days per week do you spend greater than 30 continuous minutes engaged in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing?

0 1 2 3 4 5 6 7

How many days per week do you engage in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing for less than 30 continuous minutes but more than 0 minutes?

0 1 2 3 4 5 6 7

How many total hours do you spend per week engaged in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing?

- None to less than 1 hour
 1 hour to less than 3 hours
 3 hours to less than 5 hours
 5 hours to less than 10 hours
 10 hours or greater

 Missed Question(s)

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Do you ever limit your participation in physical activities because of your heart condition? Yes No

What type(s) of sports or activities? Contact sports
 Heavy weight lifting
 Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
 Competitive sports
 All activity
 (Select all that apply)

Why is your participation in contact sports limited? Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of your heart condition
 You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
 You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
 You are limited by conditions other than your heart

What are your concerns in regards to contact sports? Concern that something bad could happen to you while engaged in the activity
 Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis
 (Select all that apply)

Why is your participation in heavy weight lifting limited? Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of your heart condition
 You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
 You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
 You are limited by conditions other than your heart

What are your concerns in regards to heavy weight lifting? Concern that something bad could happen to you while engaged in the activity
 Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis
 (Select all that apply)

Why is your participation in intense aerobic activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of your heart condition
- You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
- You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
- You are limited by conditions other than your heart

What are your concerns in regards to intense aerobic activity?

- Concern that something bad could happen to you while engaged in the activity
- Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis (Select all that apply)

Why is your participation in competitive sports limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of your heart condition
- You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
- You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
- You are limited by conditions other than your heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to you while engaged in the activity
- Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis (Select all that apply)

Why is your participation in all activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of your heart condition
- You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
- You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
- You are limited by conditions other than your heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to you while engaged in the activity
- Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis (Select all that apply)

Missed Question(s)

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Are there activities that you would like to participate in but do not due to your medical condition?

Yes No

What type(s) of sports or activities?

- Contact sports
 Heavy weight lifting
 Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
 Competitive sports
 All activity
(Select all that apply)
-

Why is your participation in contact sports limited?

- Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of your heart condition
 You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
 You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
 You are limited by conditions other than your heart
-

What are your concerns in regards to contact sports?

- Concern that something bad could happen to you while engaged in the activity
 Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis
(Select all that apply)
-

Why is your participation in heavy weight lifting limited?

- Symptoms during activity
 Not enough energy to participate
 Concern that the activity would not be tolerated because of your heart condition
 You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
 You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
 You are limited by conditions other than your heart
-

What are your concerns in regard to heavy weight lifting?

- Concern that something bad could happen to you while engaged in the activity
 Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis
(Select all that apply)
-

Why is your participation in intense aerobic activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of your heart condition
- You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
- You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
- You are limited by conditions other than your heart

What are your concerns in regard to intense aerobic activity?

- Concern that something bad could happen to you while engaged in the activity
- Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis (Select all that apply)

Why is your participation in competitive sports limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of your heart condition
- You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
- You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
- You are limited by conditions other than your heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to you while engaged in the activity
- Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis (Select all that apply)

Why is your participation in all activity limited?

- Symptoms during activity
- Not enough energy to participate
- Concern that the activity would not be tolerated because of your heart condition
- You could participate (good energy and no symptoms with the activity) but you are restricted by your cardiologist
- You could participate (good energy and no symptoms with the activity) but you are restricted by your parents and/or guardian
- You are limited by conditions other than your heart

What are your concerns in regard to all activity?

- Concern that something bad could happen to you while engaged in the activity
- Concern that it would be harmful/unhealthy for you to participate in the activity on a frequent basis (Select all that apply)

 Missed Question(s)

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 Your Cardiologist Recommendations

How often does your cardiologist discuss activity recommendations or restrictions with you?

- Never
 Some clinic visits
 Most clinic visits
 All clinic visits
-

Does your cardiologist discuss specific activities or exercises that s/he recommends? Examples could include recommending specific physical activities such as soccer or bike riding or specific exercises such as leg strengthening routines.

- Yes No
-

Are there specific activities that s/he restricts?

- Yes No
-

What type(s) of sports or activities does s/he restrict?

- Contact sports
 Heavy weight lifting
 Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
 Competitive sports
 All activity
 (Check all that apply)
-

Does s/he give specific goals for time spent in activity? Examples could include recommending that you participates in activity for at least an hour at a time or recommending overall activity goals of 60 minutes per day for at least four days per week.

- Yes No
-

Does s/he give specific goals for intensity of activity? Examples could include recommending running on a treadmill with a goal speed, riding an elliptical or stationary bike with a goal RPM, or participating in activity with the goal of increasing heart rate to a certain goal or until sweating.

- Yes No
-

 Single Ventricle Clinic Cardiologist Recommendations

How often does the cardiologist that you see in the single ventricle clinic discuss activity recommendations or restrictions with you?

- Never
 Some clinic visits
 Most clinic visits
 All clinic visits
-

Does s/he discuss specific activities or exercises that s/he recommends? Examples could include recommending specific physical activities such as soccer or bike riding or specific exercises such as leg strengthening routines.

- Yes No

Are there specific activities that s/he restricts? Yes No

What type(s) of sports or activities does s/he restrict?

- Contact sports
- Heavy weight lifting
- Intense aerobic activity (sustained endurance activities such as running, swimming, and other activities often referred to as "cardio")
- Competitive sports
- All activity

(Select all that apply)

Does s/he give specific goals for time spent in activity? Examples could include recommending that you participates in activity for at least an hour at a time or recommending overall activity goals of 60 minutes per day for at least four days per week. Yes No

Does s/he give specific goals for intensity of activity? Examples could include recommending running on a treadmill with a goal speed, riding an elliptical or stationary bike with a goal RPM, or participating in activity with the goal of increasing heart rate to a certain goal or until sweating. Yes No

Missed Question(s)

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How important do you think physical activity is to your health and quality of life?

- Not important at all
 - Somewhat important
 - Important
 - Very important
 - Extremely important
-

How interested are you in physical activity?

- Not interested at all
 - Somewhat interested
 - Interested
 - Very interested
 - Extremely interested
-

Do you feel like your cardiologist's recommendations regarding physical activity are:

- Much too restrictive
- A little too restrictive
- Just right
- A little too lenient
- Much too lenient

To what extent do each of the following factors limit your activity beyond the restrictions recommended by your cardiologist?

Missed Question(s)

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	Significantly	Moderately	Somewhat	Very little	Not at all
I do not have enough energy to participate in the activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have symptoms with physical activity (lightheaded, dizzy, blurry vision, chest pain, palpitations, and/or passes out)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am not interested in physical activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My parents or guardians are concerned that the activity is not safe for me because of my heart condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned that the activity is not safe for me because of my heart condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not have access to activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For various reasons, some patients choose to participate in activities against the recommendations of their cardiologist. Do you participate in activities that the cardiologist recommends against?

Yes No

Why?

Belief that I can participate without increased risk

Belief that while there is increased risk involved with the activity, the benefits of the activity outweigh the increased risk.

What benefits do you believe exist in participating in the restricted activities?

Improved physical fitness

Weight loss

Improvement in energy

Improvement in mood and/or decrease in stress, anxiety, or depression

Decreased risk of chronic health conditions such as high blood pressure, high cholesterol, and diabetes

Social interaction with other people
(Select all that apply)

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Over the past few years have the recommendations from your pediatric cardiologist changed regarding physical activity?

Yes No

What recommendations has your pediatric cardiologist started making regarding physical activity?

- My pediatric cardiologist started recommending specific activities or exercises. Examples could include recommending specific physical activities such as soccer or bike riding or specific exercises such as leg strengthening routines
 - My pediatric cardiologist started discussing the benefits of physical activity but has not recommended specific activities or exercises
 - My pediatric cardiologist started limiting my participation in physical activity
-

What reason does your pediatric cardiologist give for the new recommendations?

- Benefit of physical activity for patients with a Fontan operation
 - Benefit of physical activity for general health, but not specific to having had a Fontan operation
 - Concern for recent changes in my heart that may make physical activity dangerous for me
 - My pediatric cardiologist did not give a reason for the new recommendations
 - Other
-

What other reason does your pediatric cardiologist give for the new recommendations?

Have you changed your physical activity level based on these changed recommendations from your pediatric cardiologist?

Yes No

What changes have you made to your physical activity level based on the recommendations of your pediatric cardiologist?

- I have started participating in organized sports
 - I have started a specific workout routine such as lower extremity weight training at the gym
 - I have started participating in or increased my participation in active but not strenuous activities such as going for a walk or leisurely riding my bike
 - I have started participating in or increased my participation in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing
 - I have stopped participating in organized sports
 - I have stopped participating in a specific workout routine such as lower extremity weight training at the gym
 - I have decreased or stopped my participation in low energy activities such as going for a walk or leisurely riding my bike
 - I have decreased or stopped my participation in activities that involve higher levels of exertion such as running, playing soccer or basketball at the park, skateboarding, weight lifting, or skiing
- (Select all that apply)

Missed Question(s)

At least one question on the prior page was not answered. If you intended to skip this question (or questions), please proceed with the questionnaire. If skipped in error, please click on Previous Page to go back to answer the skipped question(s).

Thank you for your participation in this survey!

Thank you for your participation in this survey!

No Consent / Assent

You selected 'I do not Consent / Assent'. If this was selected in error, please click the Previous Page button and select 'Start Survey'.

If you are under age 18, your parent / guardian must be aware you are taking this survey (and be available to answer any questions you might have, if under age 15) before you can complete this survey.