Phoenix Comprehensive Assessment of Pectus Excavatum Symptoms (PCAPES)

Neurological Symptoms:

A. Do you have headaches?
- ○ (0) No, I do NOT have headaches.
- ○ (1) Yes, 1 or less times per month.
- ○ (2) Yes, several times per month.
- ○ (3) Yes, more than once per week.
- ○ (4) Yes, at least once daily or majority of the time with activity.

B. Do you have cold hands and feet?
- ○ (0) No.
- ○ (1) Yes, several times per month.
- ○ (2) Yes, at least three times per week.
- ○ (3) Yes, at least once daily or majority of the time with activity.

C. Do you notice color changes in your hands or feet (red, white, blue, purple) when exercising?
- ○ (0) No.
- ○ (1) Yes, occasionally when I perform these types of activities.
- ○ (2) Yes, often when performing these types of activities.
- ○ (3) Yes, majority of the time I am performing these activities.

D. Do you experience dizziness when running or performing aerobic type exercise?
- ○ (0) No.
- ○ (1) Yes, occasionally when I perform these types of activities.
- ○ (2) Yes, often when performing these types of activities.
- ○ (3) Yes, majority of the time I am performing these activities.

E. Do you experience dizziness when walking upstairs, hiking hills, biking or doing other exercises where you are leaning forward?
- ○ (0) No.
- ○ (1) Yes, occasionally when I perform these types of activities.
- ○ (2) Yes, often when performing these types of activities.
- ○ (3) Yes, majority of time I am performing these activities.

F. Do you experience dizziness or feel like you are going to pass out when you stand up?
- ○ (0) No.
- ○ (1) Yes, several times per month.
- ○ (2) Yes, at least 3 times per week.
- ○ (3) Yes, at least once daily or majority of time with activity.

G. Do you experience numbness in your hands and feet?
- ○ (0) No
- ○ (1) Yes, several times per month.
- ○ (2) Yes, at least 3 times per week.
- ○ (3) Yes, at least once daily or majority of time with activity.

Total Score Neurological Symptoms: / 22

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Cardiovascular Symptoms (Exercise related):

A. Are you able to keep up with your peers (friends same age) during exercise or work?

- ○ (0) Yes, I can keep up with my peers.
- ○ (1) Yes, I can keep up with my peers, but I am much more "winded" and tired.
- ○ (2) No, I can keep up for a short time but then fall behind.
- ○ (3) No, I can NOT keep up with my peers when doing exercise or sports.

B. Are you able to hike up a hill or climb a flight of stairs?

- ○ (0) Yes, no limitations or symptoms.
- ○ (1) Yes, I experienced symptoms however I can push through.
- ○ (2) Yes, but experience symptoms that cause me to stop.
- ○ (3) No, unable to do any of these activities due to symptoms.

C. Are you able to swim for a long distance/time?

- ○ (0) Yes, no limitations/symptoms or do not perform for other reasons.
- ○ (1) Yes, but experience symptoms I can push through.
- ○ (2) Yes, but experience symptoms that cause me to stop.
- ○ (3) No, unable to, due to symptoms.

D. Are you able to run or play strenuous sports for a long distance/time?

- ○ (0) Yes, no limitations/symptoms or do not perform for other reasons.
- ○ (1) Yes, but experience symptoms I can push through.
- ○ (2) Yes, but experience symptoms that cause me to stop.
- ○ (3) No, unable to, due to symptoms.

E. Are you able to run, swim, or play sports for a short distance/time?

- ○ (0) Yes, no limitations/symptoms or do not perform for other reasons.
- ○ (1) Yes, but experience symptoms I can push through.
- ○ (2) Yes, but experience symptoms that cause me to stop.
- ○ (3) No, unable to, due to symptoms.

F. Are you able to exercise?

- ○ (0) Yes, I am able to exercise as much as I want to without symptoms.
- ○ (1) Yes, but I am limited in how much or how long I can work out due to symptoms.
- ○ (2) I can lift weights but unable to do any cardio or aerobic exercise.
- ○ (3) I am NOT able to do exercise of any type because of my symptoms.

G. Are you able to do light chores and housework such as dusting and laundry?

- ○ (0) Yes, no limitations or symptoms.
- ○ (1) Yes, but experience symptoms I can push through.
- ○ (2) Yes, but experience symptoms that cause me to stop.
- ○ (3) No, unable to, due to symptoms.

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Cardiovascular Symptoms:

A. Do you have difficulty climbing stairs due to symptoms of shortness of breath, dizziness, or heart pounding?

- ○ (0) No.
- ○ (1) Yes, but I am still able to climb without stopping and resting.
- ○ (2) Yes, but I need to stop and rest at least once during climb, fine after resting.
- ○ (3) Yes, it would be difficult for me to climb more than 2 flights of stairs.

B. Do you experience palpitations (feeling of skipping or irregular fast heartbeats)?

- ○ (0) No.
- ○ (1) Yes, occasionally (several times per month).
- ○ (2) Yes, multiple times per week.
- ○ (3) Yes, daily or majority of time with activity.
- ○ (4) Yes, frequently even when lying down or resting.

C. Does your heart race so fast that it feels like it will "jump out of your chest"?

- ○ (0) No.
- ○ (1) Yes, occasionally during exercise.
- ○ (2) Yes, often during exercising.
- ○ (3) Yes, frequently even when I am not exercising.

D. Do you experience heart symptoms when you are sitting or resting?

- ○ (0) Not at all.
- ○ (1) Yes, occasionally when I am sitting or resting.
- ○ (2) Yes, often when I am sitting or resting.
- ○ (3) Yes, almost all of the time when I am sitting or resting.

E. Do you experience chest pain?

- ○ (0) Not at all.
- ○ (1) No more than occasional aches and pains.
- ○ (2) Yes, with certain positions or during exercise.
- ○ (3) Yes, most of the time.

F. Are you limited in how long you can perform any type of exercise due to symptoms?

- ○ (0) No.
- ○ (1) Yes, occasionally when I perform any exercise.
- ○ (2) Yes, often when performing any exercise.
- ○ (3) Yes, majority of the time I am performing any exercise.

Total Score Cardiovascular Symptoms: __ / 40

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Pulmonary Symptoms:

A. Do you feel pressure or difficulty breathing after sitting for some time?

- ○ (0) No, I do not have this feeling or symptom when sitting.
- ○ (1) Yes, but I am still able to sit for long periods.
- ○ (2) Yes, but I need to get up occasionally due to symptoms.
- ○ (3) Yes, and I cannot sit for long periods of time due to symptoms.

B. Do you feel like you cannot "catch" your breath or breathe enough when exercising?

- ○ (0) No, I do not have this feeling or symptom when exercising.
- ○ (1) Yes, but I can push through and do as much exercise as I want.
- ○ (2) Yes, but I can push through the symptoms for a while, but I am limited in my ability to exercise.
- ○ (3) No, I am unable to do exercise due to these breathing symptoms.

C. Do you feel like you cannot take a deep breath or breathe normally?

- ○ (0) No, I do not have this feeling or symptom.
- ○ (1) Breathing feels restricted occasionally during the day.
- ○ (2) Breathing feels restricted during exercise.
- ○ (3) Breathing feels restricted all the time.

D. Do you get lung infections or pneumonia?

- ○ (0) Rarely.
- ○ (1) Yes, I did frequently as a child but rarely now.
- ○ (2) Yes, at least once – twice per year.
- ○ (3) Yes, more than 2 times per year.

E. Have you been diagnosed or told you have asthma?

- ○ (0) No.
- ○ (1) Yes, as a child but NOT now.
- ○ (2) Yes, I was prescribed inhalers, but they do NOT help, or I do not have/use them.
- ○ (3) Yes, I need to use inhalers to help make breathing better.

Total Score Pulmonary Symptoms: __ / 15

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Gastrointestinal Symptoms:

A. Do you experience trouble with swallowing food or pills because they feel stuck?

- ○ (0) No, not at all.
- ○ (1) Yes, occasionally with certain foods or large pills.
- ○ (2) Yes, often when swallowing large bites or pills.
- ○ (3) Yes, majority of the time when swallowing any solid food or pills.

B. Do you feel "full" after eating?

- ○ (0) No, not at all, unless I overeat.
- ○ (1) Yes, occasionally when eating a meal.
- ○ (2) Yes, always with a large meal and sometimes with a small meal.
- ○ (3) Yes, I am unable to eat more than small meals due to feeling full quickly.

C. Do you feel short of breath after eating a large meal?

- ○ (0) No, not at all.
- ○ (1) Yes, slightly, or occasionally after eating a large meal.
- ○ (2) Yes, often after eating a large meal.
- ○ (3) Yes, every time I eat a meal and I feel the need to limit the amount I eat due to symptoms.

Total Score Gastrointestinal Symptoms: __ / 9

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Psychosocial Symptoms:

A. Do you feel like your chest deformity is causing you fatigue?

- ○ (0) No, I do NOT have fatigue.
- ○ (1) Yes, I have some fatigue but do not feel it is related to my chest.
- ○ (2) Yes, I feel like I have more fatigue than my peers due to my chest, but I still can do most things.
- ○ (3) Yes, I have significant fatigue due to my chest that affects my ability to do most things.

B. Do you feel like your chest causes you to suffer anxiety?

- ○ (0) No, it does NOT make me anxious.
- ○ (1) Yes, I was anxious because of my chest as a child or teen but minimally now.
- ○ (2) Yes, sometimes, it is dependent on the situation.
- ○ (3) Yes, majority of the time my chest causes me significant distress and anxiety.
- ○ (4) Yes, all the time and I need to take medication because of this anxiety.

C. Do you feel like other people, especially physicians, have dismissed your symptoms?

- ○ (0) No, I do NOT feel my symptoms have been dismissed.
- ○ (1) Yes, sometimes, it is dependent on the situation.
- ○ (2) Yes, often.
- ○ (3) Yes, and this made me have significant feelings like I was “crazy” or felt others thought I was “making it up”.

D. Does the look of your chest bother you?

- ○ (0) No, it has never bothered me.
- ○ (1) Yes, as a child routine but minimally now.
- ○ (2) Yes, sometimes, but it is dependent on the situation.
- ○ (3) Yes, often and it causes me significant distress.

E. Have you ever wished you could hurt yourself or be dead because of how your chest looks?

- ○ (0) No, it does NOT cause me any of these feelings.
- ○ (1) Yes, as a child or teen but not now.
- ○ (2) Yes, sometimes, it is dependent on the situation.
- ○ (3) Yes, often, daily.
- ○ (4) Yes, and I have injured myself in the past because of these feelings.

F. Does the look of your chest make you feel sad or depressed?

- ○ (0) No, it does NOT affect my mood.
- ○ (1) Yes, as a child or a teen but minimally now.
- ○ (2) Yes, sometimes, it is dependent on the situation.
- ○ (3) Yes, the majority of the time how my chest looks causes me to feel sad or depressed.

G. Do you avoid activities where your chest can be seen?

- ○ (0) No, never.
- ○ (1) Yes, as a child or a teen but not at all now.
- ○ (2) Yes, sometimes.
- ○ (3) Yes, I do NOT do anything where my chest can be seen.

Total Score Psychosocial Symptoms: __ / 23

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