Patient and Family Guide to

Chest Wall Reconstruction

for Pectus Excavatum







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The PECTACULAR Team

Our pectus excavatum patients and our chest wall reconstruction team are experiencing spectacular results--that's why we call our patients and our program **PECTACULAR!**

The PECTACULAR Team includes:



YOU*!!!



Your Surgeon and Extenders



Physical Therapists



Dietitians



Nursing Staff



Operating Room Staff



Pain Management Team



Occupational Therapists



^{*}You are an integral part of our team! To achieve the best chest wall reconstruction outcome, we need you to complete all of your responsibilities and participate as an engaged team member.

^{*}You can commit to our team by signing the enclosed patient-physician contract at the conclusion of our meeting



PECTACULAR Pre-hab

PRE-HAB: rehabilitation that begins before surgery

Pre-hab for Chest Wall Reconstruction:

- improves chest wall flexibility
- stretches and strengthens to improve post-op mobility
- reduces post-op pain
- enables parent to safely assist with post-op mobilization

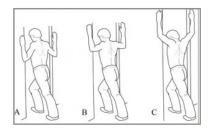
Our pre-hab program includes both home exercises and a formal consultation with a physical therapist. You will need to pick up your pre-hab prescription at the conclusion of our informational meeting.

Pre-hab Home Exercises

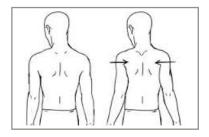
At least daily you should do the following stretches:



Hamstring Stretches: your hamstrings are the muscles on the back of the thigh. You can stretch several different ways, there are three pictured above. Hold each stretch for 30-45 secs, repeat 3 times



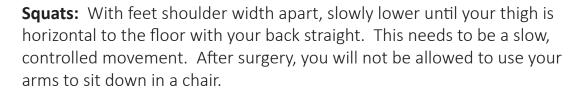
Anterior Chest Wall Stretch: Stand in a corner with forearms on wall. Lean chest into the wall. Stretch for 45 secs 3 times. Take slow deep breaths.



Upper Back Strengthening: Squeeze shoulder blades together and hold for count of 3. Do 2 sets of 15.

PECTACULAR Pre-hab







Backwards Sit-Up: Do a sit-up with your knees bent. Then slowly lower back down to the floor.

Deep breathing: 10 deep breaths, 5 times a day. See chart on next page.

List 5 activities that involve:

Trunk Rotation (turn to flush the toilet while you are sitting on it)

Trunk flexion (bending over to tie your shoes)

Lifting arms higher than your shoulders (washing your hair)



PECTACULAR Pre-hab

30-Day Deep Breathing Exercise Chart

Take ten deep breaths, inhaling deeply and holding your breath for three seconds. Do this at least five times daily. Use this chart to keep track of your exercises by placing a check mark in the appropriate box when completed. This exercise helps to stretch the chest wall muscles and reduces post-operative pain.

Date	Breakfast	Lunch	Afternoon	Dinner	Bedtime

PECTACULAR Nutrition

Optimal nutrition promotes healing and enhances the reconstructive outcome. Be conscientious of having a balanced diet. This includes appropriate protein and calorie intake, plenty of fruits, vegetables, whole grains, and lean meats. Post-operatively, you will need a high calorie, high protein diet for recovery. Exact needs will vary, but a general guideline is **2,000 calories** and **150 grams of protein** daily.

While in the hospital, you will have orders for high calorie, high protein diet and Ensure® drinks. We recommend you bring some of your favorite high calorie, high protein snacks to supplement this. Initially, you may have a decreased appetite and will need to consume approximately **200** calories every two to three hours. Remember, you may resume your usual diet 10-14 days after surgery in order to avoid unnecessary weight gain.

Suggestions include:

- Recovery or Meal Replacement Bars
- Trail Mix
- Greek Yogurt
- Hummus
- Nut Butter
- Jerky



Bar Allergy Questionnaire

The minimally invasive Nuss procedure for pectus excavatum requires an internal brace. The bar is a stainless steel alloy. A non-infectious wound complication may occur in the presence of metal allergy, which could jeopardize the reconstruction. For this reason, we use the following process to screen for metal allergy:

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1.	Do you have a history of sensitivity/allergy to metals (nickel, cobalt, gold, etc) or leather products? Yes No
2.	Do you get itch/burning from metal parts that come into contact with your skin, for exampl from costume jewelry, buttons, coins, tools, cell phones, wrist watches, etc? ☐ Yes ☐ No
3.	Do you get rash from metal parts that come into contact with your skin, for example from costume jewelry, buttons, coins, tools, cell phones, wrist watches, etc? \[\sum \text{Yes} \sum \text{No} \]
4.	Do you get itch/burning with exposure to leather products (shoes, belts)? ☐ Yes ☐ No
5.	Do you get rash with exposure to leather products? ☐ Yes ☐ No

If you answered yes to any of these questions, please discuss with your surgeon.



One Week Before Surgery

Pack your bags! Plan for a 5 day hospital stay.



We recommend packing:

- OVERSIZED pajama-style button up shirt OR a t-shirt that is twice your size
- Slip-on shoes
- Sockwell Compression socks
- Loose shorts or pants with an elastic or drawstring waist
- Boppy pillow (found in infant section in stores)
- U-shaped travel neck pillow
- High protein/calorie snacks
- Lip balm/chapstick

Reduce post-operative pain. Continue your home exercise program. Remember, simple deep breathing exercises help stretch chest wall muscles and reduce post-operative pain.

Prevent surgical site infection with preoperative chlorohexidine (CHG) showers. These will begin 3 days prior to your operation. See page 10 for complete instructions.

Prevent post-operative constipation. We recommend all patients take an over-the-counter Dulcolax® (bisacodyl) suppository or Senokot® (senna) orally the morning of the day before surgery. This helps prevent post-operative constipation by inducing a preoperative bowel movement.

Prevent post-operative nausea by applying a prescribed Scopolamine patch the night before surgery. Wash your hands after application. Be sure to fill this prescription early as it may require a prior-authorization.

Purchase Clear Gatorade/Powerade to consume the night before and the morning of surgery (see page 11.) Purchase snacks to bring for your hospital stay (see page 7.) Full purchase list is available as a loose sheet in the folder.

Decrease anxiety by feeling prepared. Children's surgery will call the business day before your surgery and inform you of times to stop eating and drinking, and of your arrival time.



Three Days Prior to Surgery: CHG Shower

Preoperative showering with chlorohexidine (CHG) reduces bacterial skin colonization and decreases the risk of surgical site infection. Purchase a **16 ounce 4% CHG preparation**, over the counter at a retail pharmacy. Follow the directions below.



Begin 3 days prior to surgery and complete the fourth shower the morning of surgery.

- Wash and rinse your hair, face, and body in your usual shampoo and soap.
 Rinse thoroughly to remove residue.
- Turn off the shower.
- Pour a quarter size amount of the CHG soap onto a clean, wet washcloth. Apply to your body from the neck down, except genital area.

 Do NOT apply to your hair, face, or genitals.
- Wash for 3 minutes. Apply more CHG soap as needed, using ¼ of the bottle for each shower. Avoid scrubbing your skin too hard.
- Wait one minute. Turn the shower on and rinse completely with warm water.
- DO NOT use your usual soap after the CHG soap.
- Air dry as much as possible, then pat dry with a freshly laundered towel.
- Dress in freshly laundered clothes after each shower.
- Sleep on clean bed linens the night before surgery.
- Do NOT apply lotion, deodorant, powder, or perfume.
- Do NOT shave or remove any hair below the neck.

*If you have acne that affects your back or chest, begin our skin care program immediately. If you do not see improvement after 2 weeks, follow up with Dr. Smith.

Preoperative Shower Checklist		
3 days before		
2 days		
1 day		
Day of surgery		

Night before and Day of Surgery



Set your alarm! Reduce anxiety by allowing plenty of time to prepare and arrive.



Remember your bags packed with loose clothing, compression socks, pillows, and snacks. *Patient will need their Boppy and neck pillow during their first PT session, the morning after surgery (POD#1).



Prevent surgical site infection by completing your preoperative CHG bathing (see previous page.)



Prevent post-operative nausea Sports drinks like Gatorade and Powerade contain a complex carbohydrate that keeps your body in a fed rather than fasted state. Please remember, no red, blue or purple colors. We recommend clear or light colors.

The night before surgery drink 16oz of Gatorade at bedtime.



The day of surgery drink 16oz of Gatorade 2 hours prior to scheduled arrival time.

Please, use the free valet service today.



The Operation



While you are in surgery, your family will be directed to the closest available waiting area. Only 2-4 close family members are allowed in the waiting area. All other guests may wait in the public waiting areas or cafeteria.

After surgery, you will initially recover in the post anesthesia recovery unit (PACU) and then be transferred to pediatric intensive care (PICU).

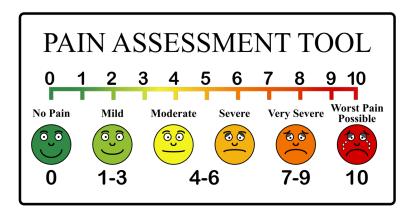
Please note; we believe your post-operative needs for monitoring and pain control require intensive care nursing. We do NOT anticipate your condition to be critical.

While you are in PICU:

- You will have several monitors in place.
- You will also receive pain medications through an IV and by mouth.
- You will have a catheter in place to drain your bladder.
- You will be able to sip clear liquids and eat toast, crackers and hard candy.
- You will lie flat in bed with only a small, flat pillow under your head.
- You will not be allowed to twist your body, bend at the waist or raise your arms beyond a level that is parallel with the floor.

Recovery in the Hospital

Instantly changing the shape of your chest wall will cause pain. We will need your feedback to adjust our approach and achieve the best pain control for you.



A variety of medications will be used to control your pain (more info on pages 16 and 18).

Once you have recovered from anesthesia and pain control is adequate, our physical therapy team will assist you in getting out of bed to a straight-back chair.

The first time out of bed may cause dizziness and nausea and you may be exhausted after only a few minutes.

Once out of bed, you may eat a regular meal, if desired. You will need a high calorie, high protein diet for your recovery, (this is where those snacks come in handy!)

You will continue your deep breathing exercises frequently.

When pain control goals are met, you will be converted to oral medications and the catheter draining your bladder will be removed.

Physical therapy and occupational therapy will work with you and your family multiple times each day. PT will progress safety and independence with transfers and upright functional mobility, including increasing your tolerance to walking and climbing stairs. OT will work closely with you and your family to safely accomplish daily activities, including toileting, dressing, and showering. You will be taught how to complete all therapy tasks while maintaining your mobility restrictions throughout. Your success with PT and OT is integral in your transition from surgery to safely discharging home.

While in the hospital, you will need to have your parking card validated to avoid unnecessary charges.

At discharge you will receive several prescriptions, including one for a chest x-ray. You will need the x-ray prescription when you come back for your first visit so keep it handy. You can also access the prescription via Epic MyChart.

Recovery in the Hospital: Therapy Guide

Caregiver Expectations

Physical therapy typically begins the morning of POD#1 (the morning after surgery), and PT and OT will continue to provide therapy multiple times each day.

- A caregiver must be present for all sessions in order to receive proper training and education.
- Caregivers are expected to be an active participant in therapy sessions, and should be able to assist in lifting the patient.
 - o Please notify your surgeon BEFORE the operation if you have any personal lifting restrictions or injuries that would prevent your ability to participate, so that proper safety arrangements can be made.

Activity Restrictions

These mobility restrictions prevent shifting of the Nuss bar(s) which could result in failure of the reconstruction. All family members and friends assisting in your care need to be well informed of your restrictions.

- You must only lay FLAT on your back, with a small, flat pillow under your head.
 - o NO sidelying or laying on your stomach.
- NO rotating or twisting the trunk.
- NO bending at the waist.
- NO weight bearing through your arms. You should avoid any lifting, pushing, or pulling.
 - o Lifting should be limited to only daily tasks, such as lifting a water bottle.
- NO raising arms beyond 90 degrees, or beyond a level parallel to the floor.
- You must only sit in a straight back chair.
- You must complete all sitting, standing, and walking with military posture.

Use the list of goals on the next page as a mobility checklist to ensure that you and your family are meeting all of your therapy milestones in preparation for a safe discharge home.

Pectacular Therapy Milestones

- You and your family can explain all of the mobility restrictions.
- Your family can perform the two-person transfer.
- Your family can help you to a chair.
- Your primary caregiver can perform a one-person transfer.
- Your family can help you get to the bedside commode.
- You can sit up for one hour.
- You can complete self-feeding and grooming tasks, within all set mobility restrictions.
- You can walk 250 feet.
- You can dress yourself, including a t-shirt.
- You can demonstrate safety with shower transfers and mobility required to perform all personal hygiene.
- You can go up and down a flight of stairs with your family guarding for safety.

CONGRATULATIONS! You are PECTACULAR!

Pectacular Approach to Pain

Medications to prevent, reduce, and alleviate pain:

- Local anesthetic
- Regional block
- Narcotic
- Muscle relaxant
- Non-steroidal anti-inflammatory

Nonpharmacologic measures to reduce and alleviate pain:

- Heating pad
- Distraction
- Massage
- Heel and elbow pads

Medications to address troublesome side effects of pain medications:

- Anti-emetics
- Stomach acid suppression
- Laxative

Parents and caregivers: Be sure to conduct skin assessments regularly, checking heels and elbows to make sure they do not have redness from pressure. Use heel and elbow pads, as needed, to protect and prevent injury to these pressure points. A memory foam topper for the patient's bed may also help alleviate pressure.

If any sores or ulcers develop contact Dr. Smith's nurse at 423-267-0466 during business hours.







Recovery at Home: Activity

Continue your activity restrictions. These restrictions prevent shifting of the Nuss bar(s) which could result in failure of the reconstruction. All family members and friends assisting in your care need to be well informed of your restrictions:

- Lying/sleeping flat with no pillow under your head while in bed, you may use a small pillow under your knees (4-6 weeks)
- No bending at the waist (4-6 weeks)
- No weight bearing through your arms. You should avoid any lifting, pushing, or pulling (4-6 weeks).
- No rotating or twisting the trunk (12 weeks)
- No raising the arms beyond a level parallel to the floor (6 weeks)
- Sitting in a straight back chair only (6 weeks)
- Sitting, standing, walking with military posture

Other activities that will be restricted for 3-6 months include karate, judo, gymnastics, contact sports, and heavy lifting (including backpacks.) You will develop a plan for physical therapy, core strengthening, and resuming physical activities during your follow-up visits.

Suggested home routine for progressively increasing activity: Consider this information as the MINIMUM amount of activity you should perform. ALWAYS do more if you feel up for it!

Home Days 1-3

Wake up each morning for breakfast, and sit up for 2 hours.

Nap if needed before lunch.

Get up for lunch and sit up in straight back chair for another 2 hours.

Nap before dinner.

Get up for dinner, take a shower, and stay up and awake until bedtime.

Home 1 week

By the end of your first week home from the hospital, you should be limited to 1 nap per day, and aim to walk for at least 10-15 minutes each day.

Home 10-14 days

At this time, you will meet with Dr. Smith for your 1st follow-up since your hospital discharge! Remember to bring your chest x-ray prescription and get an x-ray before your appointment (see page 20.)



Each day, walk within your home for at least 5 minutes. Remember, it is important to have someone with you while you walk in case you lose your balance or become dizzy or nauseated, in order to prevent a fall.



Tools to make daily activities easier and safer during your NUSS recovery - as recommended by your occupational therapist

Remember that all NUSS precautions must be followed- no twisting, bending at the waist, raising your arms above 90 degrees, no lifting over 5 lbs- when you are completing your activities of daily living. As a result, some daily tasks, like toileting and showering, may be difficult to complete following your surgery. OT will discuss the following list with you and your family during your hospital stay.

Toileting

For those with short arms, it may be difficult to wipe your bottom without twisting your trunk. Here are a few useful tools that could help limit the amount of assistance you need:

- Frida Mom Upside Down Peri Bottle
 - Available for purchase at Walmart, Target, Amazon.com
- Bidet
 - Available for purchase at Walmart, Target, Amazon.com





Showering

After surgery, you will not have as much energy, and it may be difficult to stand to take a full shower; you will also require assistance to wash your lower body and bottom. Here are a few useful tools that could help limit the amount of assistance you need:

- Shower chair
 - For walk in showers, recommended to have a back rest to promote good posture
 - Available for purchase at Walmart, Target, Amazon.com
- Tub Transfer Bench
 - For tub- shower combos, recommended to have a back rest to promote good posture
 - Available for purchase at Walmart, Target, Amazon.com
- Long handle sponge/loofah
 - Allows you to wash your own legs and feet
 - Available for purchase at Walmart, Target, Amazon.com







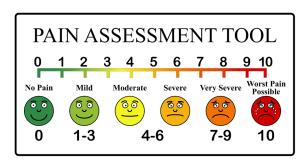
Recovery at Home: Medications

On the next page is a log to record your medications and pain scale. Please bring this to all follow-up appointments.

- **Non-steroidal anti-inflammatory** You will be given prescription strength ibuprofen. This should be taken around the clock as prescribed to achieve the desired anti-inflammatory response. It is important to take this with food.
- **Stomach acid suppression** Anti-inflammatory medications and the stress of surgery can take a toll on the stomach. To protect the stomach, you will need to take an H2 blocker, such as ranitidine (Reglan / Marinol)
- Narcotic pain reliever You will be given a prescription for oxycodone/acetaminophen (Percocet®). Continue to take one pill every four hours around the clock, as you did in the hospital. You will have a second pill to use as needed. Be aware that this narcotic pain reliever contains acetaminophen (Tylenol®) and do not take over-the-counter acetaminophen within four hours of oxycodone/acetaminophen. Do not exceed four grams of acetaminophen in 24 hours. *Note that narcotic refills cannot be called in. If you foresee a need for a narcotic refill, you will need to make arrangements for an office visit. Please call Dr. Smith's nurse at 423-267-0466 during office hours.
- **Muscle relaxant** You will be given a prescription for diazepam (Valium[®].) This relieves muscle tightness and spasm and is therefore very effective for chest wall pain. Depending on your hospital regimen, you may need to take this at regular intervals or you may use on an as needed bases.
- Laxative Narcotics and reduced activity slow bowel motility significantly and can lead to problematic constipation and distention of the colon. Polyethylene glycol (MiraLax) is a colorless, odorless, gritless powder that is added to a liquid of your choice and may be adjusted to achieve a desired effect of a soft bowel movement every couple of days. Continue your regimen of 1 capful in 16 ounces of liquid daily. Additionally, on your first day home you will take 6 capfuls mixed in 32oz of Gatorade. If this does not result in a bowel movement, you may then use an over-the-counter bisacodyl (Dulcolax®) suppository or 150mg Colace 1-2 times daily, as needed.

Instructions for medication chart:

Document pain using pain scale with scheduled and as needed pain medications



Home Medication Chart

	Scheduled pain med	As needed pain med	Muscle relaxant	As needed muscle relaxant	Anti- inflammatory	Stomach acid suppression	Laxative
Date/ Time	oxycodone/ acetaminophen (Percocet) 5mg tablets everyhours Must be given at scheduled intervals	oxycodone/ acetaminophen (Percocet) 5mgtablets everyhours Give as needed	diazepam (Valium) 5mg tabletstablets every hours Must be given at scheduled intervals	diazepam (Valium) 5mg tablets tablets every hours Give as needed	Ibuprofenmg every 8 hours Give 3 times a day	Marinol / Pepcid Daily at bedtime	MiraLax 6 caps in 32oz liquid day after discharge, then 1 cap 1-2 times daily in 8 oz liquid Colace 150mg 1-2 times daily As needed

Recovery at Home: Follow Up

Monday- Friday 8am-5pm, Call (423) 267-0466 and ask for Dr. Lisa Smith's nurse for:

- fever greater than 101°F
- continual cough
- redness, drainage or swelling at the incision sites or under the arms
- sores or ulcers (especially on pressure points like heels and elbows)
- any difficulty breathing

If these problems occur after hours or on weekends, please use Dr. Smith's cell phone.

It is important to the team that these issues are addressed right away—we want your recovery to go well!

You will follow up with Dr. Lisa Smith 10-14 days after surgery. The same day as your appointment with Dr. Smith, you will need to get a chest x-ray in the Children's radiology department. Bring the prescription form for the x-ray that you received from the hospital at time of discharge. Arrive and register in the lobby by Children's Emergency Department 45 minutes- 1 hour before your scheduled appointment with Dr. Smith. You may need to remind the x-ray technician of your activity restrictions. After your x-ray, continue to your scheduled appointment with Dr. Smith at the University Surgical office (C elevator, 3rd floor)

We aim to prescribe the appropriate quantity of medications of discharge. Please keep in mind that narcotic refills cannot be "called in." If you foresee a need for a narcotic refill, you will need to make arrangements for an office visit. Please call Dr. Smith's nurse at 423-267-0466 during office hours.

In case of emergency:

- CPR may be performed. More external force may be necessary due to the surgical bar.
- Defibrillation for cardiac arrhythmia may be performed. Anterior/posterior placement is necessary.
- CT examination can be performed. The bar may cause artifact if the CT is of the chest or upper abdomen.
- Activation of alarm systems, such as those in airports, may occur. Surgical steel bar is internal and not palpable

Post-Reconstruction Pectacular Milestones

Shower at **72 hours** or when the catheters are removed; must be done before discharge

2 weeks: Steri-strips off -- dressing off at appointment with Dr. Smith

4 weeks: Sleep on side or chest, twist at waist

6 weeks: May drive, begin light cardiovascular training (activities without risk of chest trauma)

8 weeks: Light upper body training (no more than 2-5 lbs)

3 months: Carry a backpack, non-contact sports, gradually increase weight lifting

6 months: Restriction-free, may ride roller coaster and play contact sports

3 years: Bar Removal

Helpful Lists and Links

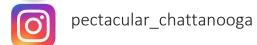
l week before surgery:
☐ Fill Scopolamine prescription
□ Buy 4% CHG solution
☐ Begin CHG showers 3 days prior to your surgery
□ Continue your Home Exercise Program
 □ Anticipate a phone call from Children's Surgery regarding arrival times and times to stop eating and drinking the business day before your scheduled surgery □ Purchase drinks, snacks, boppy pillow, neck pillow □ Pack bag □ Remember, recliners are not appropriatemake sure you have a straight back chair that supports the head.
Packing List:
 □ Oversized PJ style button up shirts OR a t-shirt that is twice your size. □ Elastic or drawstring waist pants □ Slip-on shoes
Cookwell compression socks
□ Boppy pillow □ U-shaped neck pillow with micro-beads □ High protein snacks of choice □ Lip balm/chapstick
L day before surgery:
■ Morning: Dulcolax or Senna■ Bedtime: Drink 16oz of Gatorade/Powerade
Continue daily CHG shower
☐ Evening: Apply Scopolamine patch
☐ Follow directions regarding eating and drinking provided in the phone call from
Children's Surgery
The day of surgery:
□ Complete your 4th CHG shower
☐ Drink 16oz of Gatorade/Powerade 2 hours prior to scheduled arrival time

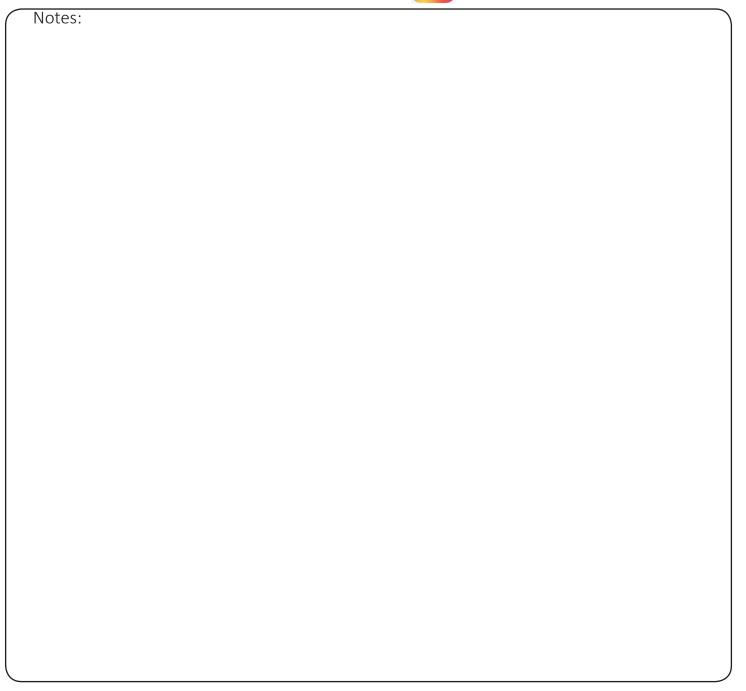
Helpful Lists and Links













We are glad you are part of our Pectacular team!

We can't wait to see your physiological, psychological, and cosmetic reconstructive results after your chest wall reconstruction!